

**IS IT FEASIBLE? SELF-AFFIRMATION FOR
HEREDITARY BREAST AND OVARIAN CANCER GENETIC COUNSELING**

by

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ABSTRACT

Background:

In recent years there has been increased understanding of the genetic factors that predispose people to cancer. While this increase in knowledge can improve patient health, patients, who are at increased risk for cancer, face decisions about testing, cancer screening, communication with family members, and even prophylactic surgery.

Statement of problem:

As more people face these decisions it is important for genetic counselors to support them in the decision-making process. Self-affirmation interventions may be an effective way to improve hereditary breast and ovarian cancer (HBOC) genetic counseling patient-centered outcomes. The study described is a randomized controlled trial to assess the feasibility of implementing a SA intervention in a cancer genetic counseling clinic.

Methods:

This study was conducted in a hereditary cancer clinic at St. Luke's Health System in Kansas City, Missouri. Patients who attended the clinic for a genetic counseling session, were randomized to completed a SA intervention or a control writing exercise beforehand and a survey of patient-centered outcomes afterward. Counselors completed a patient empowerment assessment after each appointment. The primary feasibility outcomes were patient acceptance of the SA intervention, patient attrition, and the effectiveness of the SA intervention. Secondary outcomes

were: decision self-efficacy, intentions to talk with family, genetic test uptake, patient empowerment, and HBOC knowledge.

Results:

All patient participants reported that the intervention did not interfere with their appointment (35/35). Coding analysis of patient essays showed that those who were in the intervention group were significantly more affirmed than those in the control group ($p \leq 0.01$). None of the secondary outcomes were statistically significantly different between the control and intervention groups. Patient and counselor scores on the empowerment measure were not significantly correlated ($p = 0.298$).

Conclusions:

Given our findings, follow-up studies, such as a phase II study is needed to enhance our understanding of SAs usefulness in buffering patients from the threat of cancer. Future studies should include more diverse populations and if SA is effective in the cancer setting, additional studies in other subspecialties of genetic counseling will be important prior to generalizing evidence across specialties.

Keywords: Self-affirmation, HBOC, genetic counseling, intervention, feasibility study

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INTRODUCTION

Breast cancer is the most prevalent cancer in women, with 236,968 new diagnoses in 2014 alone (U.S. Cancer Statistics Working Group, 2016). In recent years there has been increased interest in understanding the environmental and, particularly, the genetic factors that predispose people to cancer. As a result, many genes have been identified that contribute to cancer predisposition. While this increase in knowledge can improve patient health, patients who have a genetically increased risk for cancer face difficult decisions about genetic testing, cancer screening, communication with family members, and even prophylactic surgery. As more people are faced with these decisions it is important for genetic counselors to enhance the process of patient decision-making.

SELF-AFFIRMATION

Self-affirmation (SA) is a social science intervention that may be a novel way to improve patient decision-making and the genetic counseling process. SA theory is based on the concept that people work to maintain their perceptions of themselves as moral and consist persons, with high self-integrity (Sherman & Cohen, 2006; Steele, 1988). Self-integrity is an individual's perception of efficacy across multiple domains, defined further as their cumulative moral and adaptive adequacy or, maybe better understood, as their global self-efficacy (Steele, 1988). When people experience a threat to their self-integrity they naturally seek to neutralize the threat. The process of self-integrity protection can be best understood in context. For example, a woman may feel threatened by a negative health finding, but if she feels competent in her relationships and work, then her overall self-integrity is maintained and she can address the threat in a prudent and non-defensive

manner. On the other hand, when self-integrity is compromised, and other areas of self-concept do not stabilize the threat, then individuals may defend themselves against the threatening message to protect their self-integrity (Sherman & Cohen, 2006; Steele, 1988). For example, they may try to discredit or ignore a concerning message.

SA theory suggests that self-affirming people prior to facing a threat can reinforce their self-integrity and increase receptivity to the threatening message (Sherman & Cohen, 2006). Several SA techniques have been used in education and health communication research that have validated and shown promising effects of SA theory.

HEREDITARY BREAST AND OVARIAN CANCER

Hereditary breast and ovarian cancer (HBOC) is one of the earliest identified, best understood, and the most prevalent cancer syndromes. It is estimated that 5-10% of women with breast cancer and 20% of women with ovarian cancer carry a gene variant that predisposes them to these cancers (Campeau et al., 2008; Walsh et al., 2011). HBOC can be caused by pathogenic variants in *BRCA1* and *BRCA2*. Women with pathogenic variants in these genes have a lifetime risk of developing breast cancer between 40% and 80%, with a lifetime risk for ovarian cancer between 11% and 40% (Petrucelli et al., 2013). In addition to *BRCA1* and *BRCA2*, multiple other genes, including, *PALB2*, *CHEK2*, *ATM*, *BRIP1*, *RAD51C*, and *RAD51D* have been associated with hereditary breast and/or ovarian cancers, with varying levels of penetrance, each lower than *BRCA1* and *BRCA2* (Walsh et al., 2011). Women are often identified to be at increased risk of HBOC based on their family or personal history of breast and ovarian cancers. These women are then referred for genetic counseling and offered genetic testing. Those who

have been diagnosed with HBOC have family planning, prophylactic surgery, screening, and a myriad of other medical and family communication decisions to make.

GENETIC COUNSELING FOR HBOC

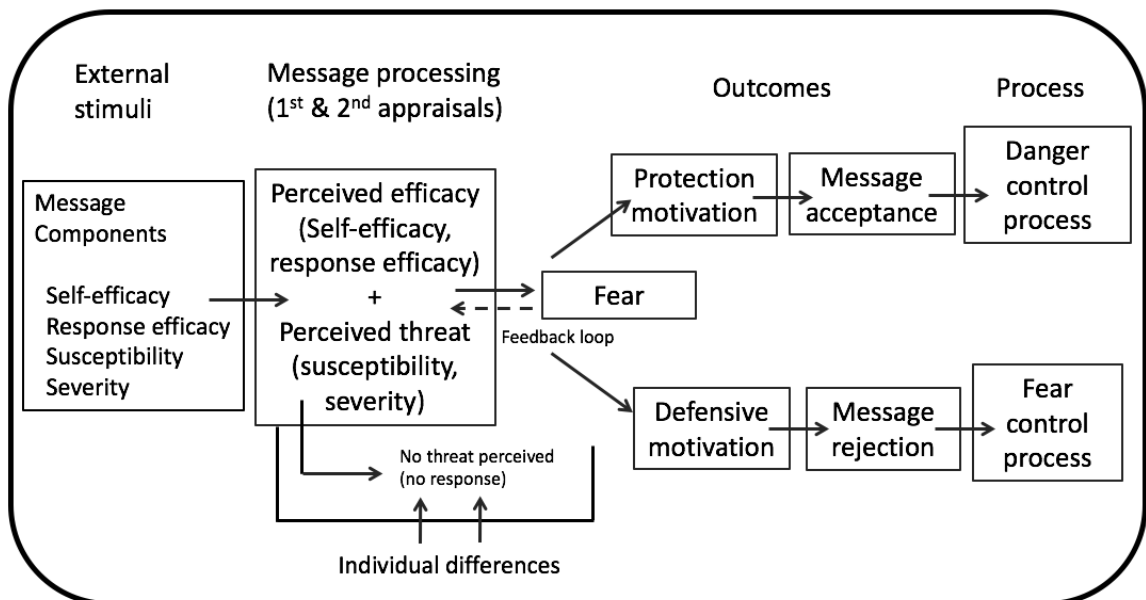
Often, communication about genetic risk, decision making, and treatment are guided by genetic counselors, who are experts at calculating genetic risk estimates, HBOC education, and counseling and facilitating patient-centered decision-making. With the growing number of genes associated with hereditary cancers, genetic counseling services are becoming more in-demand and counselors are having to see more clients in less time. Interventions before a counseling session may help to facilitate decision-making and to shorten session length. In this study, we examine the feasibility of a pre-session self-affirmation intervention aimed at facilitating patient empowerment, decision self-efficacy, and improving patient behavioral outcomes.

CONCEPTUAL FRAMEWORK: THE EXTENDED PARALLEL PROCESS MODEL

Outcomes for this study were informed by the Extended Parallel Process Model (EPPM). The EPPM is often used as a framework in communication and fear appraisal research. This model simplifies individuals' responses to fear-inducing stimuli to two components: perceived threat and perceived efficacy. As shown in Figure 1, this theory states that when people are faced with a risk message, they process it by weighing their perceived efficacy against the perceived threat (Maloney, Lapinski, & Witte, 2011). Perceived efficacy is conceptualized as an individual's beliefs about being able to avert the threat and overcome the situation. Perceived threat is conceptualized as the combination of individuals' beliefs about how susceptible they are to the threat and how severe they believe the threat to be. Similar to SA theory, if individuals perceive that their

efficacy to manage a threat is sufficient, then they accept the risk message and engage in protection motivation to reduce the risk of the threat. If instead, individuals perceive that the threat is greater than their efficacy to manage it, then they engage in a defensive motivation and attempt to minimize or discredit the threatening message. The EPPM has been used extensively to inform fear and risk control communication studies and aligns with the SA model (Maloney, Lapinski, & Witte, 2011). A study by Napper, Harris and Klein (2014) showed that the SA process moderates the variables in the EPPM. They also found that including SA in the EPPM increases the model's explained variance.

Figure 1. Extended Parallel Process Model (Maloney, Lapinski, & Witte, 2011)



Genetic counseling sessions are often focused on genetic risk and susceptibility information. Therefore, it is possible that clients who perceive this information to be threatening may defend themselves against the information in genetic counseling sessions

to minimize the perceived threat. Reinforcing a client's sense of self before a genetic counseling appointment may promote information acceptance and communication within the session.

PRIMARY OUTCOMES BACKGROUND: FEASIBILITY

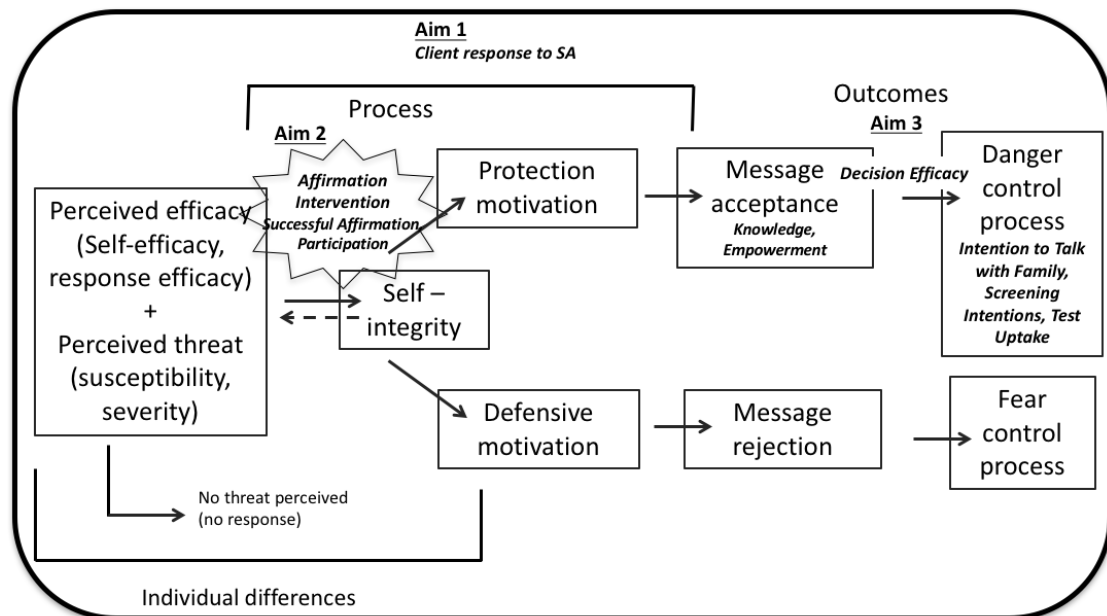
To our knowledge no research has examined the impact of a SA intervention in genetic counseling (Etchegary & Perrier, 2007). There is one study that assessed the link between spontaneous SA and genetic risk information seeking. This study of 594 participants in the ClinSeq cohort found that those who were higher in spontaneous self-affirmation were more likely to seek out genetic risk information despite being high in anticipated affect (Ferrer et al., 2014). Anticipated affect is a correlate for worry. These results suggest the value of further research.

Given the lack of intervention research in this context it is important to conduct a feasibility study (phase I) prior to a full-scale (phase II) intervention study to assess: favorable outcomes, clients' reactions to the SA intervention, and the logistics of and barriers to SA implementation. Feasibility research studies generally have smaller sample sizes and therefore statistically significant outcomes are not expected. These studies allow for exploration of many aspects of implementation and preliminary outcomes. The National Cancer Institute has recognized the need for more intervention-based feasibility studies prior to full-scale studies to determine "whether comprehensive and multilevel evaluations are justified (Bowen et al., 2009, p. 1)." A feasibility study of SA in genetic counseling would allow for preliminary examination of the impact of SA on genetic counseling outcomes to provide estimates of effect size and, consequently, the necessary sample size for a future study.

SECONDARY OUTCOMES BACKGROUND

Based on what we know about genetic counseling for HBOC, the EPPM and self-affirmation theory, a SA intervention may be anticipated to increase patient behavioral intentions to minimize the threat of HBOC cancer and acceptance of threatening messages about their cancer risk. The field of genetic counseling has outlined acquisition of knowledge, psychosocial support, facilitating family communication, and aiding in decision making as goals for patient encounters (Bernhardt, Biesecker, & Mastromarino, 2000). Combining our study model and genetic counseling goals for this study, we chose to measure post-visit knowledge, decisional-efficacy, empowerment, genetic test intentions, screening intention, and intentions to talk with family about cancer risk as outcomes of a self-affirmation intervention. Figure 2 shows how the selected outcomes fit within the EPPM.

Figure 2. Conceptual framework based on Extended Parallel Process Model (ad. Maloney, Lapinski, & Witte, 2011)



Self-Efficacy and Empowerment

Based on the EPPM and the literature, SA has the potential to improve patient self-efficacy and empowerment. At this time only one study has addressed implementing SA specifically in a medical encounter. This randomized controlled trial of SA in 99 African American patients with hypertension found that the SA treatment group requested and provided more information about their medical condition from their primary care provider in a medical encounter (Havranek et al., 2012). Recordings of the patient-provider interactions were assessed using Roter Interaction Analysis System (RIAS) coding. In the SA group, the patient-provider communication was characterized as being more interested, friendly, responsive, interactive, and respectful. These results give evidence that patients may be more engaged in a genetic counseling conversation and have higher decision-making efficacy after a SA exercise.

Behavior Intentions

Research in SA suggests that SA may increase patients intentions to pursue testing and intentions to talk with family. Behavior intentions following genetic counseling are particularly important since they A study of 84 participants assessing message degradation and behavior intentions found that patients who were self-affirmed and were at risk for type II diabetes were more likely to intend to pursue online type II diabetes risk information (van Koningsbruggn & Das, 2009). Additionally, they were less likely to affirm the statements: “The message was exaggerated,” “The message was too extreme,” and “The message was distorted” in relation to a health message about type II diabetes risk. This indicates that those at increased risk of diabetes were more accepting

of the threatening message and more likely to intend to seek out their risk information. These effects were not found in the low-risk group.

Taber et al.'s (2014) work with the ClinSeq cohort found that patients lower in spontaneous SA and higher avoidance tendencies showed lower intentions to learn a genetic testing result ($p = 0.001$). Furthermore, they found that participants who were also high in avoidance tendencies but instead higher in spontaneous self-affirmation had lower information avoidance ($p < 0.001$).

Ferrer et al.'s (2015) work with the same cohort found that those who were higher in spontaneous affirmation were significantly more likely to intend to share actionable results ($p = 0.05$) and non-actionable results ($p = 0.01$) with family members. Although spontaneous SA is distinct from prompted SA, this finding could suggest that an intervention would also increase discussions with family members. Additionally, SA interventions have been shown to significantly increase participants' feelings of love and connectedness to others compared to a control group, which may also be related to intentions to talk with family (Crocker, Niiya, & Mischkowski, 2008).

Knowledge

Several studies have shown that SA increases patients' decisions to seek out threatening information regarding their health; demonstrating a greater openness to the threatening message. A study of 40 university students found that those who were self-affirmed were more likely to choose to receive risk results for a hypothetical condition than those who were not affirmed ($p < 0.01$) (Howell & Shepperd, 2012). This study was repeated and validated by Howell & Shepperd (2017) in two follow-up studies.

In one study 66 women were given an article to read stating that coffee consumption increases the risk for fibrocystic breast disease half of the women were given a self-affirmation exercise focusing on kindness before reading the article (Reed & Aspinwall, 1998). Those who drank coffee and were self-affirmed oriented to and accepted risk confirming information significantly more quickly than did coffee drinkers who were un-affirmed. Other studies have shown similar results related to accepting threatening health messages (Harris & Epton, 2009). As previously mentioned, specific to genetic information, findings from the ClinSeq cohort found that those who were higher in spontaneous self-affirmation were more likely to report seeking out genetic risk information despite being high in anticipated affect (Ferrer et al., 2014). Since SA can increase message acceptance and motivation to avoid the threat, it is consistent that clients may attend to the threatening message more carefully and remember information about HBOC more accurately (Harris & Epton, 2009).

INTERVENTION RESEARCH

Intervention research in genetic counseling is in its infancy. The majority of intervention research in genetic counseling compares information delivery models, such as online, tele-counseling, and in-person models (Athens, et al., 2017). A systematic review of randomized control studies in genetic counseling found only 27 articles between 1990 and 2015 that assessed ‘enhancements’ to genetic counseling practice. The type of enhancements varied widely, including decision aids, genetic counseling as an enhancement to standard care, adding a psychosocial element to genetic counseling through a social worker, culturally sensitive genetic counseling, personalized risk assessments, etc. This review found that the intervention research had widely varying

degrees of rigor and quality, with a need for more systematic, quality research. The field of genetic counseling needs to establish a tradition of quality research that is based on the generations of work in education, patient care, and counseling. Quality feasibility studies can help to establish what intervention work from these fields are justifiable to invest resources for a fully powered study. The current study is a strong step towards evidence based practice in genetic counseling.

SIGNIFICANCE

Our study applies SA in a novel clinical setting, broadening the research trajectory in both SA and genetic counseling. SA interventions are simple, evidence based, and theory driven; when applied to HBOC genetic counseling they have the potential to easily and efficiently improve patient care.

Objective

The objective of this study is to investigate whether a self-affirmation intervention is feasible and demonstrates potential to be effective in the context of genetic counseling, therefore justifying a phase II study.

Specific Aims

1. To describe patients' responses to a novel SA intervention, including perceived impact, barriers, and facilitators to implementing such an intervention on a wider scale
2. To assess the implementation of a SA intervention in a genetic counseling clinic based on:
 - a. The percentage of eligible clients that completed a pre-visit SA intervention

- b. If the SA intervention is effective in affirming HBOC genetic counseling clients
- 3. To assess the preliminary impact of a SA intervention by comparing outcomes between SA and control condition participants. Specifically assessing:
 - a. Behavioral outcomes: Intentions to talk with family, test uptake, intentions for follow-up mammograms
 - b. Psychosocial outcomes: Empowerment, decision self-efficacy
 - c. Knowledge outcomes: HBOC knowledge

METHODS

STUDY DESIGN

This research is an intervention-based, randomized controlled, feasibility study. HBOC genetic counseling patients received the short State-Trait Anxiety Inventory (STAI) and either a SA intervention or control writing exercise before their appointment and after their appointment completed a survey assessing the study outcome measures. Genetic counselors completed a post-appointment survey regarding the patient's empowerment, after each appointment with a patient participant.

STUDY SAMPLE

The inclusion criteria for this study was: female patients, 18 years of age or older, competent to read and write in English, and had first time genetic counseling appointment at Saint Luke's Health System's Cancer Institute in Kansas City, Missouri. Patients were eligible if they had prior genetic testing through another clinic. Participant selection was indiscriminant of whether patients had cancer or a history of cancer. For patients who do not have cancer, genetic counseling was scheduled based on family history of specific

cancers or self-referral for cancer risk. Patients were ineligible if they were being seen for follow-up appointments in the clinic because they already had a relationship with the genetic counselor.

Power Analysis: For a fully powered study assessing the effect of SA on genetic counseling outcomes, we estimated that we would have needed 296 participants to identify a small to medium effect (Cohen's $d = 0.35$) with beta of 0.85 and alpha of 0.05 (Sweeney & Moyer, 2015). To assess feasibility outcomes, we recruited 35 patients and 2 genetic counselor participants. Between 24-50 participants are needed for a feasibility study that aims to estimate a standard deviation and calculate sample size for a phase II study. For a more detailed discussion on these estimates see Sim & Lewis, 2012 and Julious, 2005.

Genetic counselor participants were the two genetic counselors employed at Saint Luke's Health System (WF, KW). They self-selected for participation after seeing an invitation to host the study on the National Society of Genetic Counselors Cancer Special Interest Group webpage.

PROCEDURES

Patient Consent

The scheduling coordinator at Saint Luke's Health System identified participants from the referral list who met the study criteria. When calling to schedule patients' appointments the coordinator asked participants if they would be interested in having a researcher contact them about participating in a study related to their genetic counseling appointment. If they consented to have their contact information shared with the research

team, the scheduling coordinator gave the agreeing potential participants' names, phone numbers, and appointment date to the student investigator (AKC). About one week prior to their appointment the student investigator called potential participants and obtained verbal informed consent (See Oral Consent Script for Client Participants in Appendix A). The student investigator left a maximum of three voicemails with the potential participant over a three-business day period. If the investigator was unable to contact the potential participant, they were considered lost to follow-up. Patients who consented to participate were randomly assigned to complete the SA intervention or control condition, by flipping a coin. After consenting, the student investigator notified the clinic scheduling coordinator which patients consented to participate. Oral consent was approved by the presiding IRB.

Intervention and Post-Appointment Survey Procedure

When patient participants checked in for their genetic counseling appointment, they were given the STAI and the SA or control writing exercise. These documents were self-administered by the patient in the waiting room directly before their genetic counseling appointment.

Genetic counselors were blinded to the study condition of the patients who participated. Counseling sessions proceeded per protocol for the clinic. As patients left their appointment, they received a paper survey regarding their demographic information (age, sex, education, race, ethnicity, cancer status), experience in the study, decision self-efficacy, empowerment, HBOC knowledge, intentions to talk with family, mammogram screening intentions, and intentions to pursue genetic testing. They were also given the option to access an electronic version of the survey. Patients who chose the electronic

version were emailed a link to the survey by the student investigator (AKC). Hard copy surveys were returned to the front desk. Electronic versions were completed via an online survey program. A week after their appointment, all patients who had not completed the in-person survey received an electronic reminder notification to complete the online questionnaire. The clinic coordinator sent the intervention/control, in-person post-surveys, and counselor surveys to the NIH by standard mail. Upon completion of the online survey or paper questionnaire participants were mailed a \$15 gift card.

Counselor Post-Appointment Survey

After each appointment with a study participant, genetic counselors completed a short patient empowerment survey in their office. Upon completion of the study Saint Luke's Health System genetic counselors were given a \$1,400 gift card as a recruitment incentive.

All procedures were approved by the National Institutes of Health review board.

STUDY INSTRUMENTS

Intervention

For the SA intervention, participants were asked to rank 11 items (artistic skills, athletics, business/money, creativity, independence, music, politics, relationships with friends and family, religious values, sense of humor, spontaneity) from most important to least important (See Appendix B) (Creswell et al., 2013; Havranek et al., 2012). They were then asked to write about the item that is most important to them, why it was important to them, and how they have used it recently. The control group ranked the same list and wrote about their 9th ranked item and why it might be important to someone else. Both groups then ranked how important the value that they wrote about was to them

on a scale of 1-7. The intervention and control conditions were consistent with the exercises used in many other SA intervention studies (Creswell et al., 2013; Havranek et al., 2012; Ferrer, Klein, & Graff, 2017).

Immediately after the intervention or control condition, participants completed the 2-minute short version of the State-Trait Anxiety Inventory (Marteau & Bekker, 1992). This measurement entails six questions to assess the participant's current state of anxiety. The purpose of the STAI was to identify if those who were more anxious were more affected by the SA intervention. The intervention and STAI were designed to take about 10-15 minutes together, we did not collect data on how long it took patients to complete the exercise. At the end of the intervention there was a detachable page asking for the participant's email address to send them the post-intervention survey and a reminder to complete it.

Patient Post-Intervention Survey

Patient post-appointment survey consisted of questions related to response to and acceptance of the SA measure as well as each outcome category (test uptake, intentions for screening, empowerment, intention to talk with family, decision self-efficacy, and HBOC knowledge). The survey was designed to take less than 15 min for participants to complete, data on how long participants spent on this measure was not collected in the clinic but was on the online version.

Response to SA measure. The patient response measure asked both open-ended and yes/no questions regarding patients' acceptance of and response to the intervention or control. There was also a single question asking if and how patients thought that the

measure affected their counseling session to identify any overt interference of the writing exercise with their session.

Decision self-efficacy. To measure decision self-efficacy, we used the Decision Self-Efficacy Scale (O'Connor, 1995). We chose this scale because it correlates with both decision conflict focusing on feeling informed and supported ($r = 0.55$), and knowledge ($r = 0.61$). Cronbach alpha ranges between 0.86-0.92 for this measure (Cranney et al., 2002; O'Connor, 1995).

Test uptake. For this section, we asked two questions to assess uptake; “Did your counselor offer you genetic testing in your counseling appointment?” (yes/no) and “If yes, do you plan to have genetic testing?” (yes/maybe/no).

Intention to talk with family. Intention to talk with family was measured using two original questions. The first is a question that asked patients to select the categorical description of the family group they were most likely to share information with from a list of options, such as “I plan to talk to only a few people who are closest to me.” The second question which stated, “How likely are you to share results with the relatives you selected?” was rated on a 1-7 likert scale labeled “extremely likely” to “extremely unlikely.”

Empowerment. Empowerment was assessed using the validated Genetic Counseling Outcomes Survey (GCOS-24) (McAllister et al, 2011). The GCOS-24 is a 24-item instrument that was designed to measure positive outcomes of genetic counseling. Empowerment in this survey is conceptualized to include decisional control, cognitive control, behavioral control, emotional regulation, and hope. The scale has seven

dimensions, which exist under a single higher order construct. Internal consistency for this measure is 0.87 (McAllister et al, 2011).

Patient Knowledge. Patient knowledge was measured using modified questions based on the National Center for Human Genome Research Knowledge scale and genome sequencing knowledge items from Kaphingst and colleagues' study of informed consent (Kaphingst et al., 2012; Scherr, Christie, & Vadaparampil, 2015). These questions focused on patient's broad knowledge needed to make an informed decision, rather than specific details, since counseling sessions may differ depending on a patient's indication for HBOC genetic counseling. Cronbach alpha for the original National Center for Human Genome Research Knowledge measure is 0.74, although this cannot be applied to our measure because of the modifications based the cancer clinical setting (Lerman et al., 1996).

Counselor After Visit Survey

The counselor after visit survey consisted of a counselor version of the Genetic Counseling Outcome Scale (GCOS-24). This scale was modified from the original GCOS-24 for use by counselors and parallels the patient version. This measure consists of 24 likert scale questions that assess counselor's perceptions of the patient's empowerment. To create this measure, the student investigator (AKC) modified the original GCOS-24 to reflect third person language regarding the patient. This measure was then reviewed by researcher BB. The student investigator and BB discussed the edits and refined them for the final version. It was designed to take 3-5 minutes for the counselors to complete after each session with a participating patient.

DATA ANALYSIS

Data were analyzed using SPSS 25.0. The primary outcome variables were related to the feasibility of the SA intervention in the cancer genetic counseling setting and secondary outcome variable related to limited efficacy testing.

Primary Outcomes

Feasibility outcomes were measured in both the intervention and control groups. Because the writing exercise was universally well received by patients, we did not analyze the data for differences in responses between groups.

To assess patients' responses to the intervention, we analyzed their answers to the feasibility focused questions in section five of the post-visit survey. This section consisted of three yes/no and three short answer questions. The yes/no questions are reported as percentage of clients who indicated yes. Only a few patients responded to the short answer questions, therefore the answers were not coded for themes. For patients who responded, their comments are reported in full. Patient recruitment is reported as percentages of eligible clients who completed each step of the study and the reason for attrition, when known.

Based on previous research by Ferrer et al. (2012) and Harris & Napper (2005), the self-affirmation essays were analyzed in several steps. The SA prompt asked patients to write about why the value that they chose was important to them and to give examples of how they used that value in their everyday lives. The student investigator (AKC) and a research trainee coded the essays for analysis. Individual statements were coded as either relating to importance, life application, or neither. The word count for statements regarding importance and life application were recorded, as well as total word count of

the essay. When the importance and life application categories appeared to overlap, they were differentiated by the mention of specific aspects of everyday life being coded in the latter category (i.e. “my husband makes me laugh during hard times”) and more general statements of importance in the former category (i.e. “friends are important because they have helped me through tough times”). Statements relaying that the value was important (e.g. “music is important to me”) or that described the value (e.g. “music and creativity go hand in hand for me”) were not included in the word count for either subcategory.

Attitude strength for the essays was evaluated by rating how important the value selected appeared to be for participants on a 7-point Likert scale ranging from “not at all” to “very.”

SA was assessed according to the raters answering the question, “setting aside your own opinions and values, how self-affirmed would you estimate the writer of this passage to have been (at the end)?” using a 5-point rating scale. A score of one was given if the essay mentioned the value but did not include: a description of how it applied to themselves, an elaboration about the importance of the value, or examples about how the writer upheld the value in her daily life. A score of five was given if the essay included an elaboration of why the value was important to the writer and several examples of how the writer upheld the value in her daily life. Scores between 2-4 were given based on amount of description about the importance of the value, application of the value to self, and number of examples. These designations were based on previous methods by Ferrer et al. (2012). Finally, any inclusion of statements about cancer, medical care, health, or their condition were noted to determine if patients were affirming on the same value as the cancer health threat.

Before analyzing the essays, the student investigator and a research trainee met to discuss the coding protocol. They each coded 10 essays independently, reviewed their codes together, and refined the coding criteria. They next coded 10 more essays and again discussed and refined the coding criteria. They then recoded the initial 10 essays independently to improve consistency. Interrater reliability for phrases discussing the importance of the value was 0.88, for phrases discussing examples of using the value was 0.98, for attitude strength was 0.96, and for SA score was 0.94. The rest of the 24 essays were analyzed only by the student investigator (AKC). Intervention/control group labeling was removed from the essay transcripts for analysis. Although, as standard for the SA intervention, those in the control group were instructed to write about others and the intervention group were instructed to write about themselves therefore, for some essays, group participation was identifiable. While we recognize this as a limitation, it is consistent with other SA research and inherent to the fidelity of the intervention; if patients in the control group wrote about themselves they would likely self-affirm on the 9th value.

Secondary Outcomes

Analysis of secondary outcome variables included a comparison between treatment and control groups of test uptake, intentions for screening, empowerment, intention to talk with family, decision self-efficacy, and HBOC knowledge in order to identify variables that would be worthwhile to include in a phase II study (See patient survey, Appendix C). Analysis of these variables was also used to determine the necessary sample size to adequately power a phase II study. Secondary outcomes were compared using linear regression. A linear regression was conducted for each secondary

outcome, where group (intervention or control) was the independent variable and the secondary outcome was the dependent variable. Education, race, and anxiety score were entered into the model as additional predictor variables. All variables with the exception of cancer status, were treated as continuous variables. Cancer status was analyzed as a dichotomous variable. Any differences between intervention/control groups that resulted in a $p\text{-value} \leq 0.05$ were considered statistically significant.

Patient empowerment was also analyzed, comparing the total score for patients and counselors using a paired-samples t-test (See section 3 of patient survey of appendix C and appendix D). The difference between control and intervention group regarding the correlation between paired patient/client surveys was not analyzed. Effect sizes and standard deviations for each outcome were identified, and an estimated sample size for a fully powered study was estimated based on the power calculations.

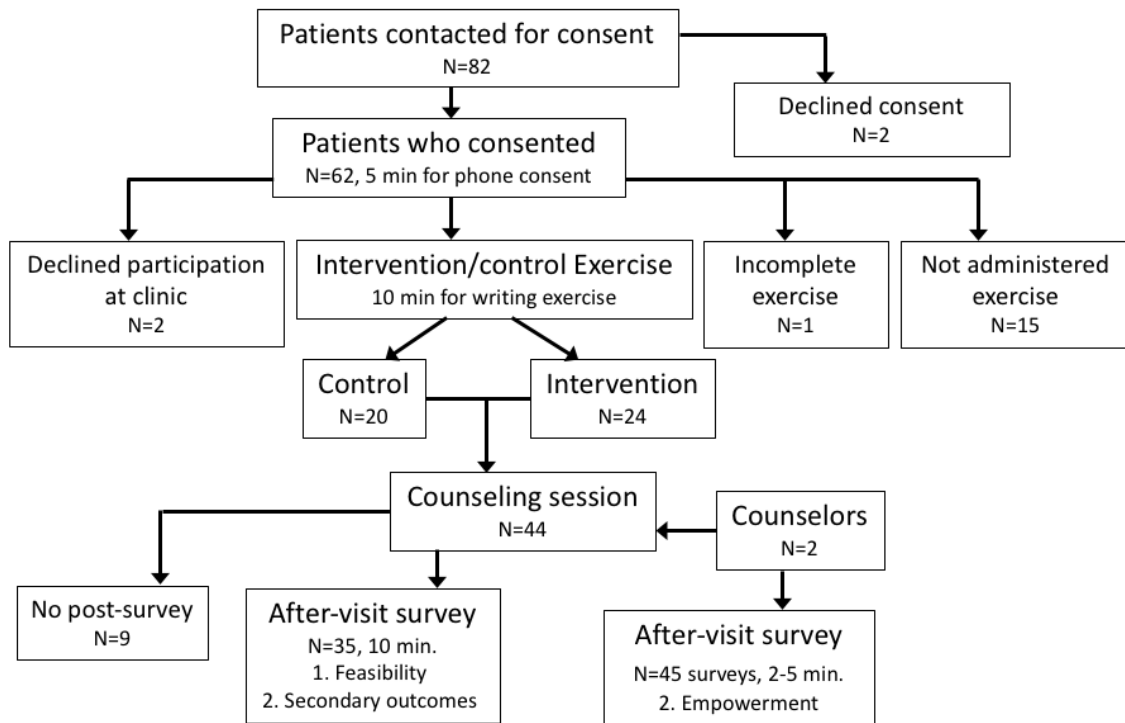
RESULTS

RESPONSE RATE

When asked by the clinic coordinator, 82 patients consented to be contacted by the student investigator (AKC). The student investigator made contact with 64 of the 82 patients, 18 were unable to be reached after 3-5 calls (a maximum of three voice messages). Sixty-two patients consented by phone. Only one patient declined consenting after completing the consent process. Another patient reported that she was unwell and asked not to finish the consent process. Additionally, two patients chose not to participate after they arrived in clinic. Of these, one was concerned that having had previous genetic counseling may affect our study and removed herself from participation. The other patient did not give a reason for declining participation. Fifteen patients, who consented,

were either late to their appointment or did not receive the intervention for other reasons, primarily related to clinic flow. Forty-four patients completed the writing exercise; one incorrectly completed the SA intervention and her data was removed from the study. Nine patients did not complete the post-appointment survey in the office or after receiving two reminder emails for the online post-survey. The attrition rate for the intervention group was 17.4% and 20.0% in the control group. Attrition rates did not differ significantly between groups ($p = 0.647$).

Figure 3: Flow Chart of Participants



Thirty-five patients completed all study procedures and were included in all statistical analyses. The counselors completed 45 post appointment surveys, which were included for analysis of the counselor version of the empowerment survey. Counselor surveys that did not have a matched patient empowerment survey were not included in

the patient/counselor empowerment correlation analysis. Of patients who agreed to be called by the student investigator (AKC) for consent 42.7% completed all study procedures. The scheduling coordinator at Saint Luke's estimated that half of patients who were asked if they would agree to be contacted for consent agreed to be contacted, but this was not quantified for the study. Participant demographics can be found in Table 1. No patients identified as Hispanic and 33 of 35 patients were offered genetic testing by counselors.

Table 1: Sample demographics

Sample Demographics					
Age	Sample size	Mean	SD		
Control	n = 11	47.73	12.81		
SA	n = 17	47.65	12.52		
Total	n = 28	47.68	12.39		
Anxiety	Sample size	Mean	SD		
Control	n = 20	2.37	0.78		
SA	n = 23	2.54	0.77		
Total	n = 43	2.48	0.78		
Race	White	African American	Other	Total	
Control	n = 16 (100%)	n = 0 (0%)	n = 0	n = 16	
SA	n = 16 (84.21%)	n = 2 (10.53%)	n = 1 (5.26%)	n = 19	
Total	n = 32	n = 2	n = 1	n = 35	
Education	High School	Some College	College Grad	Grad school	Total
Control	n = 2 (12.5%)	n = 6 (37.5%)	n = 2 (12.5%)	n = 6 (37.5%)	16
SA	n = 3 (15.79%)	n = 5 (26.32%)	n = 9 (47.37%)	n = 2 (10.53%)	19
Total	n = 5	n = 11	n = 11	n = 8	35
Cancer Status	Not had cancer	Have had cancer	Total		
Control	n = 12 (75%)	n = 4 (25%)	n = 16		
SA	n = 11 (57.89%)	n = 8 (42.11%)	n = 19		
Total	n = 23	n = 12	n = 35		

SELF-AFFIRMATION CHECK

Several procedures were done to check the fidelity of the intervention. First, patients were asked to rank the question “How important is this item to you?” a 7 point Likert scale ranging from “very important (1)” to “unimportant (7)”. The mean score for the control group was 4.60 (SD = 1.50). The highest ranking was 2 and the lowest ranking was 7. All participants in the intervention group ranked their value as 1, “very important.” Independent sample t-test analysis showed a statistically significant difference between means ($p \leq 0.01$) in the control and intervention group, indicating that patients in the intervention group considered the value that they wrote about to be statistically significantly more important to them than those in the control group. Levine’s test for equality of variances was not met ($p \leq 0.01$) therefore equal variances were not assumed for this analysis. The table below shows the distribution of values chosen by the control and intervention groups.

Table 2: Patient ranked values

Values in Essays	
Control (9th ranked value)	Frequency
Artistic skills	6
Business/Money	4
Athletics	3
Music	3
Creativity	2
Humor	1
Spontaneity	1
Intervention (1st ranked value)	Frequency
Relationships with friends and family	11
Religious values	10
Creativity	1
Independence	1

We calculated the total word-count of patient SA essays, the word-count of sentences/phrases that discussed the importance of the value, and the word count-of sentence/phrases that discussed examples of how the value was used recently. In addition, we rated the patient's attitude and affirmation strength demonstrated in their essays. There was a significant effect of the control/intervention condition on the total word-count of patient essays ($p = 0.005$). Meaning that essays were significantly longer in the intervention than in the control group. Levene's test of equality of variances was significant for this measure ($p = 0.001$), therefore equal variances were not assumed. There was not a statically significant effect of group on the word-count of patient's comments about why their chosen value was important to them ($p = 0.558$). Meaning that

patients in the intervention group did not write more about the importance of the chosen value than those in the control group. Lastly, there was a significant effect of group on the number of words patients wrote giving examples of how they used the value in everyday life ($p = 0.001$), equal variances were not assumed for this group.

Attitude strength assessed how important a value was to patients based on their essay transcript. For this measure, the coders rated how important they perceived the value to be. There was a significant effect of group on importance ratings between the control and intervention group ($p \leq 0.01$) and of group on self-affirmation ratings ($p \leq 0.01$).

Table 3: Self-Affirmation Check

Self-Affirmation Check				
	Control Mean	Intervention Mean	p -value	Levene's test
Total Word Count	26.20 words	56.96 words	$p = 0.005$	$p = 0.001$
Important Word Count	11.40 words	13.41 words	$p = 0.558$	*
Example Word Count	3.78 words	32.48 words	$p = 0.001$	$p \leq 0.01$
Attitude Strength	2.28/7	5.41/7	$p \leq 0.01$	*
Self-Affirmation Score	1.65/5	3.72/5	$p \leq 0.01$	*

* Levene's test for equality of variances was not significant and equal variances were assumed

We were concerned about patients affirming on the same construct as the hereditary cancer threat and therefore noted any direct reference to patient's diagnosis, family history, health, cancer, or medical care in their essays (Sivanathan et al., 2008).

Three patients mentioned their health stating:

“Before my cancer diagnosis, I prayed for three things- two of which were granted (my sister to have a life- saving operation and my dog to get over a debilitating disease). My third prayer/request was to not have cancer —two out of three wasn't bad for me (intervention, 71, breast cancer).”

“I left care at ---- (hospital) to see Dr. P---- because I was thinking creatively (intervention, 71, cancer).”

“I have MS. I have been blessed to always be able to maintain my independence for the past 29 years following my diagnosis (intervention, 68, no cancer).”

PATIENT-REPORTED FEASIBILITY

Patients reported their response to the intervention based on six short answer and yes/no responses questions. All patients who did the post-test questionnaire said that they were able to finish the SA exercise. All patients said that the SA exercise did not affect their visit. All patients also said that the SA exercise did not hinder their visit. Nine participants reported that the SA intervention improved their appointment. Interestingly, two of those who said that the exercise improved their appointment were in the control group.

Six participants responded to the short answer section of the surveys. Their answers can be found in Table 4. Although, there was not enough data to code the

transcripts, the patients in the control condition seemed to find the exercise to be irrelevant and annoying, while those in the intervention group seemed accepting and comfortable with the exercise.

Table 4: Patient short answer response to intervention

Group	Quote
Control	It didn't seem relevant, but (I) expect it was helpful or necessary for some reason unknown to me.
Control	It seemed very random and not at all related. Honestly, I found it more annoying than anything.
Control	Not sure how the writing activity related to my appointment. I enjoyed the activity, thought, as it made me think. 😊
Intervention	I had no qualms about completing the writing activity as I feel comfortable writing in a narrative form and do not have a problem putting my feelings in writing
Intervention	I thought it was a little odd ~ but all in the name of research! My answers came easily to me - no problem!
Intervention	I felt this was a good idea in that Counselor knows your thoughts on participating in genetic testing, good or bad!

Nine patients completed the study post-assessment online. Patients who took the survey online took an average of 10 minutes (max time 22 minutes; minimum time 4 minutes) to complete it, which was within the expected time. Time to complete the post-test was not measured for patients who completed it in the clinic.

SECONDARY ANALYSIS

Analysis of secondary patient outcomes included 16 patients in the control group and 19 patients in the intervention group. All regression analysis controlled for education, race, and anxiety scores unless otherwise indicated.

Intentions to Talk to Family

Intentions to talk to family was scored by ranking patients answers from 1-6 based on the degree of family members who they intended to tell about their genetic testing results. The mean score for those in the control group was 4.62 (SD = 1.36) and 4.89 (SD = 1.37) for those in the intervention group. Regression analysis did not show a significant effect of group on intentions to talk with family ($p = 0.150$). Of the 35 total participants, 18 indicated that they planned to talk to almost all of their family members, two indicated that they planned to talk to almost all their first and second-degree relatives who are at risk for cancer, nine indicated that they planned to talk to most of their first and second-degree relatives who are at risk for cancer, five indicated that they planned to talk with some family members, and two indicated that they planned to talk to a few people who were closest to them.

Genetic Testing Intentions

Patient-reported genetic testing intentions were scored on a scale of 1-3. A score of one indicated that they declined testing, two indicated that they may get testing, and three indicated that they would get testing. Patients in the control group had a mean score of 2.86. Two patients were not offered testing and one patient declined testing. Patients in the intervention group had a mean score of 2.67. Two patients in this group said that they may get testing, two patients declined testing, and one patient was not offered testing

based on her family/medical history. Linear regression of testing intentions between the intervention and control group indicated no significant difference between groups based on testing intentions ($p = 0.191$).

Intentions for Follow-Up Mammograms

Analysis of intentions to follow up with regular mammograms was rated on a Likert scale of 1 to 7 with the 1 being extremely unlikely and 7 being extremely likely. The control group had a mean value of 6.93 (SD = 0.26). One participant selected six, one participant had a double mastectomy and declined to answer, and the remaining reported that they were extremely likely to get mammograms. The intervention group had a mean score of 6.78 (SD = 0.73). One participant in this group selected a six and another participant selected a four, one participant had a double mastectomy and declined to answer, and the remaining reported that they were extremely likely to get mammograms. Linear regression did not show a significant effect of group on intentions for follow-up mammograms ($p = 0.90$).

Table 5: Descriptive statistics and regression for patient outcomes.

	Control			Intervention						
	Mean	N	SD	Mean	N	SD	<i>p</i>	R	R ²	SEE
Intentions to talk with family	4.62	16	1.36	4.89	19	1.37	0.150	0.496	0.249	1.26
Test uptake	2.86	14	0.535	2.67	18	0.69	0.235	0.424	0.180	0.604
Empowerment – Patient	140.56	16	16.33	140.75	19	15.51	0.301	0.429	0.042	15.48
Empowerment - Counselor	137.20	20	14.51	136.47	23	12.30	0.577	0.294	0.086	10.58
HBOC Knowledge	6.25	16	0.93	5.79	19	0.85	0.645	0.274	0.075	0.139
Decision Self-Efficacy	4.84	16	0.27	4.95	19	0.08	0.732	0.284	0.081	1.66
Mammogram intentions	6.93	15	0.73	6.78	18	0.26	0.900	0.187	0.035	0.584

- Controlled for education, race, and anxiety

HBOC Knowledge

HBOC knowledge was scored by patients receiving one point for each correct answer and no points for an incorrect answer. The maximum score on the seven questions was seven. Patients in the control group had a mean score of 6.25 (SD = 0.93). The mean score for the intervention group was 5.79 (SD = 0.85). Linear regression did not show a significant group effect on HBOC knowledge ($p = 0.274$) ($r = 0.274$, $r^2 = 0.075$).

Although not statistically significant, patients in the control group had higher raw mean scores on the HBOC knowledge measure. Eleven of 35 patients got all questions correct. Answers for individual questions are expounded on in Table 6.

**Table 6: Number of correct and incorrect answers
for patient knowledge scale**

Correct	Incorrect	Question
35	0	All people who have an altered cancer gene will get cancer
32	3	If an altered cancer gene is found, the related cancer can always be prevented or cured
27	8	The sibling or child of someone with an altered cancer gene has a 50% risk of having the same altered gene
34	1	A person whose genetic testing does not find an altered cancer gene can still get cancer
32	3	People who have genetic testing will always get clear positive or negative results
18	17	All people who have multiple family members with cancer qualify for genetic testing
32	3	If someone has an altered cancer gene, screening and healthy behaviors can reduce their risk of dying from cancer

Decision Self-Efficacy

Considering decisional self-efficacy, the control group had a mean score of 4.84 (SD = 0.27) and the intervention group had a mean score of 4.95 (SD = 0.08). Linear regression showed no significant effect of group on decision self-efficacy ($p = 0.732$) ($r = 0.284$ and $r^2 = 0.081$). Across both groups scores on this measure were high, 23 of 35 participants (65.7%) selected 5/5 on all questions. The average rating across questions for all participants was 4.90/5.

Empowerment

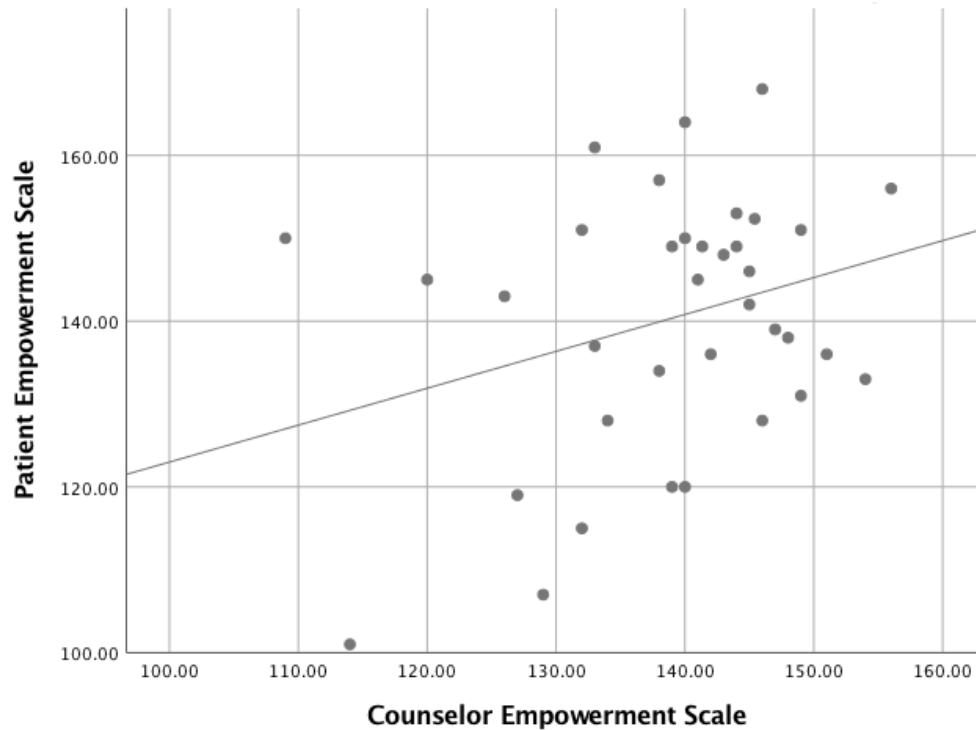
Analysis of patient completed GCOS-24 surveys showed a mean score in the control group of 140.56 (SD = 16.33) and of 140.75 (SD = 15.51) in the intervention

group. Comparing the control and intervention group through linear regression did not show a statically significant effect of group on empowerment scores ($p = 0.124$, $r = 0.450$, $r^2 = 0.203$).

The counselor completed GCOS-24 empowerment measure showed that the control group had a mean score of 137.20 (SD = 14.51) and the intervention group had a mean score of 136.47 (SD = 12.30). Linear regression comparing counselor's scores of patient empowerment did not show a significant effect of group (p -value of 0.577, $r = 0.294$, $r^2 = 0.068$). Although not statistically significant, this score was in the negative direction, indicating that the control group tended to have higher empowerment scores than the intervention group. More counselors completed the post survey than patients, with the sample size for the control group being 20 and 23 in the intervention group.

The correlation between patient and counselor GCOS-24 was analyzed using paired differences between the patient and counselor surveys, which was not statistically ($p = 0.298$, $R^2 = 0.089$). These results indicate that counselor's interpretation of their patient's empowerment does not reflect patient's impressions of their own empowerment.

Figure 4. Fit line of counselor by patient empowerment scores



Effect Size and Sample Size for Phase II Study

We calculated the effect size for intentions to talk with family since it showed the greatest trend toward significance and did not display the ceiling effect that several of the other measures showed. The effect size for intentions to talk with family was 0.20, which corresponds with a small effect size (Cohen, 1992). To detect a statistically significant ($\alpha < 0.05$) effect with based on this effect size a fully powered ($\beta = 0.85$) study would need to have 477 participants. This is larger than the 296 participants we calculated prior to completing this study based on a small to medium effect ($d = 0.35$) from other health communication SA research (Sweeney & Moyer, 2015).

DISCUSSION

The purpose of this study was to assess the feasibility of a SA intervention in a HBOC genetic counseling clinic. Secondly, we aimed to assess whether a SA intervention affected patients' behavioral intentions, knowledge, decision self-efficacy, and empowerment. SA has never been applied in a genetic counseling setting and intervention research in genetic counseling, as previously expounded on, is in its foundational stages. By addressing these questions, our research was relatively novel to both the arenas of genetic counseling and SA. Many studies have assessed SA in response to health messages but fewer have looked at SA applied in a clinical setting (Sweeney & Moyer, 2014; Havranek et al., 2012). SA has the potential to be a simple, easy to implement measure to improve genetic counseling outcomes and help patients to better access their own strengths (Crocker, Niiya, & Mischkowski, 2008; Cohen & Sherman, 2014).

FEASIBILITY OF INTERVENTION

When discussing feasibility research, it is important to keep the goals of this method of work at the forefront. In their discussion of feasibility studies, Bowen et al. (2009) outline the intentions of this work as assessing acceptability, implementation, practicality, expansion, integration, demand, adaptation, and/or limited-efficacy of an intervention. Often these outcomes do not clearly differentiate from each other so we will generally discuss how our study sheds light on each focus area.

Acceptability measures how individuals involved in administering and completing the intervention respond to the intervention (Bowen et al., 2009). Patients in this study were open to completing the SA exercise. Several patients in the intervention group

commented that they found the control exercise irrelevant or annoying, while patients in the intervention group seemed much more accepting. Patients' willingness to negatively comment in the control group, and the generally positive acceptance in the intervention group indicated that the intervention was a more acceptable exercise for patients. Patients also did not feel like the writing exercise interfered with or negatively impacted their appointment. The finding that the intervention was acceptable was consistent with prior studies of SA (Havranek et al., 2012; Sweeney & Moyer, 2014). Future work should assess the genetic counselors' opinions and responses regarding the intervention.

This study expanded research in self-affirmation beyond the populations previously studied. While there is abundant research regarding health messages and SA, to our knowledge only one other study has applied SA to a clinical setting. We demonstrated that the intervention was successful in affirming patients, and thus is worth pursuing in a phase II study in a genetic counseling setting. Doing so will broaden the application and understanding of SA theory.

Implementation and practicality assess whether the intervention was both able to be implemented as is and if it could be adjusted based on the needs of the intervention site (Bowen et al., 2009). There are several ways that SA interventions could be implemented and adjusted for broader clinical use. The simplest adjustment for clinical use is the decision whether or not to administer the intervention. Our work showed that it was easy for the clinic administration to decide, based on clinic flow, if the patient should complete the intervention or proceed directly to their appointment. While it could be argued that non-implementation is a drawback to the intervention, when thinking about broader implementation in the future we suggest that it is a benefit. Our results showed

that the intervention did not add an extra burden to patients or the clinic by utilizing the time in the waiting room for implementation. This finding may make SA more appealing to busy clinical settings, so that it is accepted where it otherwise may not be.

Because of its familial nature, we were concerned that patients who chose family and friends as their top value may self-affirm on the same construct as the threat of HBOC, which might minimize the effect of SA (Sivanathan et al., 2008). While three patients talked about their health in their essays, only one had chosen friends and family as their top value, therefore this interference was less of a factor than we anticipated although it should be considered in future work.

Adaptation is closely related to implementation and practicality. Adaptation studies look at different ways of implementing an intervention - either to improve the intervention itself or to implement the intervention in a novel real-world context. There are many different styles of SA interventions beyond the ranking and essay method that we used in our study. The most relevant adaptation for a genetic counseling clinic would be to eliminate the writing demand on patients. There are several SA interventions that present participants with a series of scales based on their values, which other studies have shown to be effective in self-affirming participants (Steele & Liu, 1983; Napper, Harris, & Epton, 2009). A similar exercise as the written one used in this study could also be administered orally. We did not choose these alternatives because they require either digital implementation or a proctor. In their 2017 article, Cameron et al. called for self-affirmation to be incorporated into the counseling session itself. A counseling method that incorporates principles of SA could be a promising path forward for SA in genetic

counseling, although attention would have to be paid to effects on the length of the session.

Integration assesses how systems need to change to implement the interventions broadly (Bowen et al., 2009). Given the ease of the SA intervention, the modifications that need to be made for an SA intervention to be more broadly implemented are relatively minimal. Some clinics have electronic check in, which could make SA more difficult to administer, but these kiosks could prompt patients to complete the intervention on screen, or could print the intervention for patients. One study used a cell phone, text message based self-affirmation intervention that could be used in a clinical setting where hard copy interventions were not possible (Arpan, Lee, & Wang, 2016). A text message intervention may not be beneficial for all populations because patients who were not familiar with texting or who had limited data plans may be less comfortable with this format.

A more formidable constraint to broader implementation is the clinical demands that limit counselors from conducting research. Many counselors have a busy clinic schedule in addition to clinical documentation, mentoring students, teaching, and working on their own research. During our study design process, the study team contacted multiple clinics local to the research institution and posted an advertisement about study participation on the National Society of Genetic Counseling Cancer SIG group. The Saint Luke's clinic genetic counselors were the only clinic who agreed to host the study at their site. This may indicate that in general counselors have clinic constraints that prohibit intervention research. Personal conversations by the student investigator with counselors indicated that many genetic counselors felt that there are significant

clinic limitations to intervention implementation. Work should be done in genetic counseling, beyond SA, to assess counselors' interest in intervention adoption in their clinic. Given the importance of evidence-based practice in genetic counseling, we need to assess and move the field forward to identify and address these limitations. Twenty years ago, quality clinical intervention research was called for, saying,

“The field should embrace data to document clients' needs, how the counseling process functions, and behavioral outcomes, as well as to evaluate the effectiveness of various counseling interventions. Without this data, it is difficult for a profession to be convincing about its importance in health care delivery (Biesecker, 1998).”

Although observational and information delivery methods (i.e. telegenetics, web-based, or in-person) research has flourished, intervention research to improve genetic counseling sessions is still limited (Athens, et al., 2017).

SECONDARY OUTCOMES – LIMITED EFFICACY TESTING

Consistent with being a feasibility study, our study was underpowered to find statistically significant results for the secondary outcomes assessed. To inform which variables would be most appropriate for a phase II study, we analyzed behavioral intentions outcomes, knowledge, decision self-efficacy, and empowerment. The chosen outcomes endeavor to address a variety of different domains that have been identified as goals of genetic counseling, namely; behavioral change, information dissemination, decision-making, and psychosocial implications (Redlinger-Grosse et al., 2016; Bernhardt, Biesecker, & Mastromarino, 2000). Our findings have several implications both for a future phase II study and for continued research in genetic counseling.

Secondary Outcomes Significance

One of the most striking findings was that we did not see any trends towards significance in the secondary outcomes, and in fact, several of the raw score findings were in the opposite direction than expected. Scores on counselor empowerment, test uptake, HBOC knowledge, and mammogram intentions were all higher in the control group than the intervention group. None of these trends were statistically significant, but the change in direction of the outcomes prompt questions about the study design and effectiveness of the intervention in this population. We chose the outcomes based on past research in SA and the Extended Parallel Processing Model, which has previously successfully been applied to understand SA theory (Napper, Harris and Klein, 2014). There are several possible explanations for these inconsistent findings, which should be addressed in future research.

The small sample size undoubtedly explains our lack of significant findings but we anticipated that the data would begin to show trends toward significance. Rather we found that several of the raw scores were in the opposite direction than expected. One explanation could be that we may have sampled a portion of the population in the control group who, by chance, were higher on these outcomes. Additionally, given the ceiling effect that was seen for decision self-efficacy, mammogram intentions and test uptake, the intervention group may have had a few individuals who indicated below average answers without a balancing effect of higher scores limited by the ceiling. There is also the possibility that the intervention lessened the social desirability bias and prompted people to more honestly report their intentions in the intervention group. This would have

given them lower scores in the intervention group but may suggest a positive effect of the intervention.

Other explanations of our ambivalent results could be that patients either were not actually affirmed by the intervention or that SA was not effective for this setting or population. Through our analysis of patient essays, we found that patients in the intervention group were significantly more self-affirmed than those in the control group. Furthermore, the same, or a nearly identical, intervention has been used in a variety of other studies which had significant findings, so it is unlikely that the intervention itself was ineffective in affirming clients (Creswell et al., 2013; Harris & Napper, 2005; Havranek et al., 2012; Ferrer et al., 2012; Ferrer, Klein, & Graff, 2017). It is possible that while numerous studies have shown positive results for SA intervention, due to publication bias, the intervention may have been weaker than anticipated. In their meta-analysis of 16 studies of SA and responses to health information Sweeney and Moyer (2014) used trim-and-fill analysis to account for publication bias. Even with this adjustment they maintained that SA was effective.

Based on past research, it is more likely that our population was as not suited to gain a benefit from SA as we predicted. The theory of SA proposes that when faced with a significant threat, if self-integrity is weak, that people will defend themselves against the threatening message. Our population may not have seen the genetic counseling appointment or their risk of hereditary cancer as a significant threat. Half of our population had already had cancer and may have viewed genetic testing as an explanation for their cancer instead of a new vulnerability in their health. It is likely that these patients had already had many more threatening experiences throughout their treatment,

so genetic counseling added a negligible threat burden. Those who had not been diagnosed with cancer may have viewed genetic counseling as a way to reduce the ambiguity of their family history and get answers, which would reduce the threat rather than raise it. In our study, we attempted to control for threat by using the STAI to measure anxiety measure. It may have been more effective to directly ask questions about how threatened (worried) patients were by the genetic counseling appointment, the risk of a hereditary cancer, or having genetic testing.

One factor that may also have affected our results was that our population was primarily white, well educated, and middle-aged. Other research has demonstrated that SA tends to be most effective for those who feel marginalized; another form of threat. Our patient participants may not have been threatened by the medical setting. A study of SA and college students' grade point average (GPA) found that Latino students in the intervention group had a higher GPA after four semesters, while this effect was not shown in for White students (Brady et al., 2016). Another study showed that SA reduced the effect of stereotype threat against women on a cognitive task, while men (who were not stereotyped) showed no difference between control and intervention groups (Martens et al., 2006). Often, genetic counseling patients are more educated, have a higher social economic level, and are early adapters so they may not feel threatened by a genetic counseling appointment. As genetic counseling is expanding to more clinics and the general population SA may become more important (Lee et al., 2005).

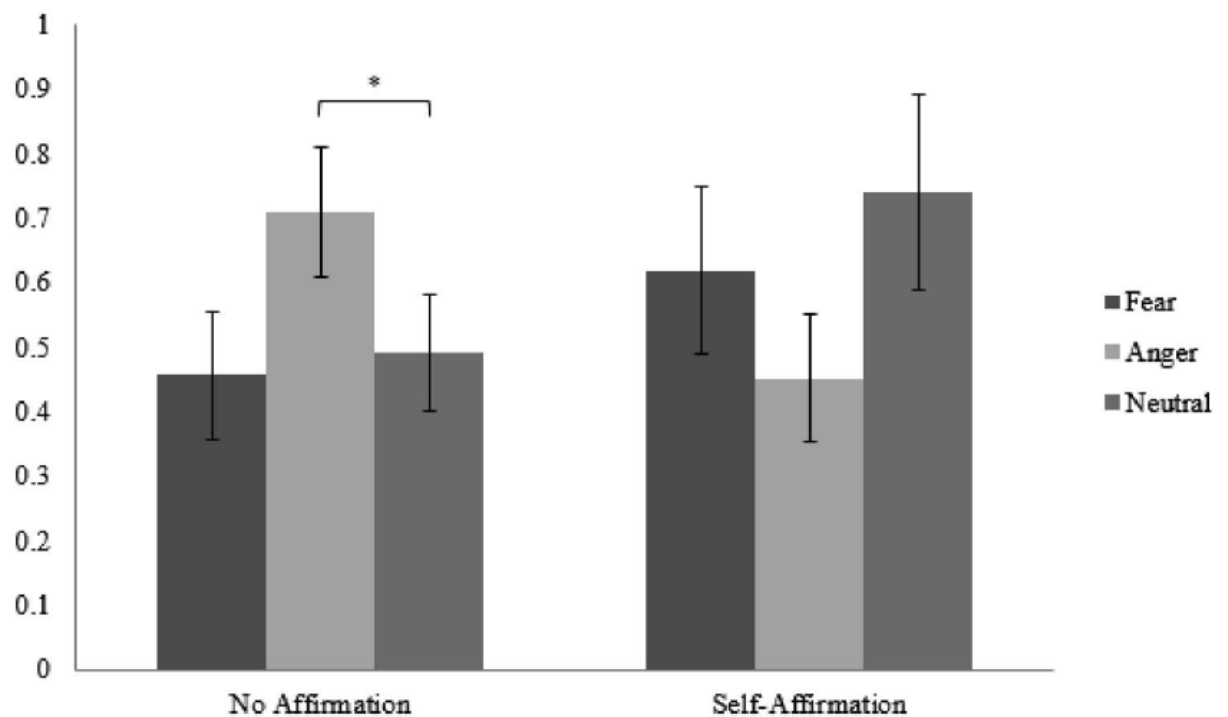
Considering both the findings from our study and other literature, it may be more effective to conduct a phase II study with African American, Latino, or other marginalized populations, where genetic counseling appointments may be more

threatening. Another consideration would be to do the study in a high risk maternal/fetal medicine clinic that sees a high proportion of patients with fetal anomalies. Many prenatal genetic counseling clinics see a large proportion of patients who are advanced maternal age or have other indications that confer a relatively minimal risk to their pregnancy, and these patients should not be included in a phase II study. We did not choose a high-risk prenatal population because of the difficulty of consenting patients who are in crisis after hearing of a likely fetal anomaly. It may be worth designing a study to reach this population because of the substantial threat these patients face, the diverse patient population, and because the majority of the decisions in prenatal genetic counseling are values based decisions. In prenatal genetics, unlike in HBOC genetic counseling, there are few treatment guidelines so the decision to continue or terminate the pregnancy is based on the patient's values.

Another consideration for a phase II study in a high risk prenatal population is that we are not aware of any research in SA that has been administered in a population in a crisis situation as would be encountered by high-risk prenatal patients. Other research has shown that anger and negative affect eliminate the positive influence of SA (Ferrer et al., 2012; Ferrer, Klein, & Graff, 2017). A recent study looked at the effect of affect on SA and behavioral change. In the study, 448 female participants who drank more than five drinks per week were induced either to be angry, fearful, or neutral (Ferrer, Klein, & Graff, 2017). They were then self-affirmed or not through a writing exercise and then given an article linking alcohol consumption and breast cancer. Interestingly, although SA significantly improved intentions in other groups, those who were angry and self-affirmed showed a trend towards being less likely to change their behavior than those

who were not affirmed ($p = 0.069$). This finding was reported after our study was conducted and measures of positive or negative emotions were not included in the present research, but future research should be designed with attention to patient affect.

Figure 5. Differences in behavior change intentions between affirmed and unaffirmed women who drink 5 alcoholic beverages a week induced to be fearful, angry, or neutral (Ferrer, Klein, & Graff, 2017).



It is uncertain how the affect surrounding the threat of having a severely disabled fetus would influence the effect of SA. SA theory would suggest that higher anxiety should make SA more beneficial, but given the other findings regarding affect the sudden extreme situation of a prenatal fetal diagnosis may have unexpected results.

Lastly, it could be argued that our findings, which are contrary to the expected outcome, bring into question the necessity and practicality of a larger study given the limited resources for research. Based on our data, we would still conclude that a phase II study that integrates changes based on our findings would be worth pursuing. We found

that the intervention was well accepted, easy to implement, and there are many questions for further analysis that could identify how to best use SA in a clinic. Furthermore, given the significant research giving credence to SA, we would suggest that a phase II study would be important to perform.

Intentions to Talk with Family

While there were not significant differences between the treatment and intervention groups, patients reported very high intentions to talk with their family compared with previous studies. Eighty-three percent of participants said that they intended to tell at least their immediate family members about their genetic testing. This is substantially higher than other literature, which has shown that patients who receive genetic counseling inform only 15–20% of their family members about their risk (Hodgson et al., 2016). In a study of 63 patients with breast or ovarian cancer at risk for HBOC, 89% said that they were against notifying distant relatives about their diagnosis of cancer and 30% were against informing close relatives of their diagnosis (Claes et al., 2003). It is unclear why our population seems more willing to share this information with their family than in previous research. It is possible that as more people become aware of genetic testing and genetic predisposition to cancers that conversations with family are easier and happen more frequently than previous research has shown. Recent research has shown that 78% of patients told their first-degree relatives about their cancer risk (Daly et al., 2016). While this is a promising change it needs to be confirmed in continued research and in other at-risk relatives.

Genetic Testing and Follow-Up Screening Intentions

As predicted, uptake of genetic testing and mammogram screening intentions were high for our population and demonstrated a ceiling effect. Our findings were consistent with past literature. One study of 302 clients eligible for BRCA1/2 testing found that 90% of clients chose to get genetic testing (Butrick et al., 2014). In the current study 84% of patients decided in favor of testing and 91% of patients said that they were extremely likely to get regular mammograms. While not significant, those in the intervention group had lower intentions on both variables, which may represent patients being more resistant to social desirability bias and more honestly reporting their intentions. We are interested to see if this trend continues in a larger study or if it occurred by chance.

HBOC Knowledge

The knowledge survey was designed to contain basic knowledge that all patients should know when leaving their genetic counseling appointment in order to make an informed decision about testing or to accurately convey information to family members. With this in mind, the survey was designed so that patients would be able to answer all questions correctly after genetic counseling. Patient scores in our study were similar to those found from the basic knowledge scales that were used to formulate the scale for this study (Kaphingst et al., 2012; Scherr, Christie, & Vadaparampil, 2015).

There were a few findings on the knowledge scale that were particularly concerning. First, almost half (48.6%) of participants said that all people with a family history of cancer qualify for testing, when in fact there are many that cancers do not indicate a genetic predisposition or where the related gene is still unknown. Misunderstanding this concept is unlikely to negatively affect a patient's health but it

may be concerning for the field of genetic counseling. If many patients believe that they have a right to testing, it undermines the need for a qualified professional such as a genetic counselor to differentiate between those who need testing and those who do not qualify. If patients are indiscriminately tested it could result in negative patient outcomes and a financial burden for patients and payers.

Three patients (8.6%) said that if a hereditary determinant for cancer is found that the related cancer can always be prevented or cured and three patients (8.6%) said that if a damaged cancer gene is found then behavior change and screening will not help to prevent the related cancer. Both of these results indicate concerning beliefs that could either lead to unrealistic treatment expectations or fatalism, which could be detrimental to a patient's medical care. These results in addition to other research showing that genetic counseling appointments are information heavy (Roter et al., 2006; Roter et al., 2009), may indicate that too much information is being given in genetic counseling appointments so that the most important information is getting lost. These findings need to be investigated in a broader patient population.

Decision Self-Efficacy

The majority of patients rated themselves very high on decision self-efficacy (mean = 4.9/5). While our study only involved two counselors, this finding may validate the value of genetic counseling in HBOC patient care. A pre/post genetic counseling decision self-efficacy study could identify if patients are generally high in self-efficacy related to genetic decision-making or if the counseling session was effective in increasing decision self-efficacy. Because of the observed ceiling effect, we would not recommend

including decision self-efficacy in a follow-up SA study. Another consideration is that our results were related to the decision self-efficacy measurement and not necessarily high decision self-efficacy in patients. While other studies have found greater variation on the same decision self-efficacy measure (Hall, Bernhardt, & Dodd, 2015; Bunn & O'Connor, 1996), ours is not the first study to observe similar ceiling effects. In their study assessing a decision aid for women choosing osteoporosis treatment, Cranney et al. (2002) found that both pre- and post- intervention the women were high in decision self-efficacy by this measure.

We chose this measure because it assessed both decision self-efficacy and efficacy in the relationship between the patient and the genetic counselor. Our intention was to measure the interaction between the patient and counselor but in a phase II study we would recommend coding audio recordings of sessions using the Roter Interaction Analysis System (RIAS) to measure patient-provider communication outcomes. Havranek et al., (2012) previously effectively applied RIAS in their study of SA with African American patients with hypertension. RIAS has previously been used to analyze patient-provider communication in HBOC genetic counseling appointments (Dijkstra et al., 2013; Ellington et al., 2005)

Empowerment

The GCOS-24 empowerment measure is a combined measure of decisional control, cognitive control, behavioral control, emotion regulation, and hope (McAllister et al, 2011). Generally, this measure can be looked at as a patient's ability to manage and interpret the impact of the genetic condition in their family. Compared with other

research using the GCOS-24 patients in our study scored slightly higher than other patients who have taken this measure (McAllister et al, 2011; Inglis et al., 2015).

Remarkably, patient and counselor scores were not significantly correlated ($p = 0.298$, $R^2 = 0.089$). While this could be an effect of our small sample size, it is concerning that counselors may not be able to accurately identify patient's self-efficacy. It would be interesting in a larger study if these results remain consistent. With more patients, it would be beneficial to assess those pairs who are most discordant and if there are distinguishing patient characteristics that precipitate counselors incorrectly assessing patient empowerment

CLINICAL IMPLICATIONS

Given that the data did not identify significant secondary outcomes, there are limited clinical applications of our work at this time. As outlined there are many questions to pursue in continued clinical research. If there were significant results in a larger study then self-affirmation interventions could be implemented before a genetic counseling appointment. Cameron et. al., (2017) suggest that counselors could incorporate values reflections into the genetic counseling appointment to decrease defensiveness. Ideally more research will be done to develop and implement self-affirmation as a freeform intervention within the counseling session. SA research could also be expanded to develop a general counseling method to help people to spontaneously self-affirm (Ferrer et al., 2014).

STUDY LIMITATIONS

This study had many limitations consistent with other feasibility work, but also had several specific limitations. The most prominent limitations are related to the sample. The sample size was comparable to many feasibility studies, but was not powered to identify statistically significant secondary outcomes. Also, the sample comprised fewer than 30% of patients who were seen in the Saint Luke's genetic counseling clinic during the recruitment period. Since we were not able to access patient information for those who did not consent to participate, we do not know if there were differences between those who participated in the study and those who did not. While the sample demonstrated a range in age, cancer status, and education, there were only two participants who identified as African American and one as native American; the remainder identified as White. According to census bureau data from 2015, 55% of residents in Kansas City, MO identified as White, 29.6% as Black, 9.7% as Hispanic and 2.85% as Asian. Even accounting for genetic counseling generally having a higher proportion of White patients, our population was skewed (U.S. Census Bureau, 2015).

Another limitation was that we chose to implement the anxiety measure after the intervention. Although this was done intentionally, so that the anxiety measure did not influence the intervention, it likely jeopardized the use of anxiety as a control. In future research, we would recommend a short survey that asks about patients' worries regarding the genetic counseling session to be completed before the SA measure.

CONCLUSIONS

Overall, the results of this study demonstrate that a phase II study of SA in genetic counseling is worth pursuing. While the secondary outcomes were not statistically

significant they suggested many questions that warrant follow-up assessment. A phase II study should include several modifications to the current design. It should not measure decision self-efficacy, but could warrant analysis of audio recordings of the genetic counseling appointments using RIAS, similarly to Havranek et al.'s (2012) work assessing differences in patient-provider communication using a SA intervention for racially discordant medical hypertension appointments. Additionally, there should be research into developing counseling techniques for incorporating SA into counseling practice. Beyond SA, there should be more research related to genetic counselor acceptance of research and interventions to improve their practice processes.

This study is a valuable step towards more intervention research related to genetic counseling processes and methods. We hope that research investigating adaptations of proven interventions in the fields of social science, counseling, and education will continue in genetic counseling. While genetic counselors have much to offer, we are a young profession and would greatly benefit from drawing on others' experiences, successes, and failures to maximize our efforts and best strengthen our practices.

APPENDICES

APPENDIX A: CONSENT FOR PARTICIPATION

ORAL CONSENT SCRIPT FOR CLIENT PARTICIPANTS

Study Title: Is it Feasible?: Self-Affirmation for Hereditary Breast and Ovarian Cancer Genetic Counseling

Principal Investigator: Lori Erby

[Greeting]. Hi, my name is Anna Chassevent, I am a researcher at the National Institutes of Health. I'm calling because you have an appointment at the High-Risk Breast Cancer clinic at St. Luke's Health System, and I think you may be eligible for a project I am doing. Is now a good time for you to talk or is there a better time for me to call back? (either continues or sets up time to call back).

Thank you. For this project, we are studying a way to improve your genetic counseling experience. We are working to see if a short writing exercise before your appointment can help improve the conversation and content in our genetic counseling appointments. You do not have to join, it is your choice. Would you be interested in hearing more about the study?

If you say yes, we will ask you to arrive 15 minutes early to your appointment and fill out a survey and a short writing exercise about things that are important to you. After your appointment, we will ask you to complete a follow-up survey either in the office or online. If to be completed online, we will give you the link to access the survey. It will take 10-15 minutes for the first survey and exercise and about 10-15 min for the follow-up survey. You may feel uncomfortable answering some of the questions. You can skip any question that you do not want to answer and you may stop at any time. We will collect your answers and use them to see if the writing exercise improves clients' experience. There will also be several questions about how you felt about the writing exercise. These will help us to know if other clients would be accepting of it in the future.

There is a risk that someone outside the study will see your information. We will do our best to keep your information safe by keeping your information on a secure computer. We will not record your name. Instead, we will ask you to create code words, when we share your information with other researchers, we will ask them to use the same protections. If you are pregnant, there are no additional risks to your fetus from participation in this study.

You may benefit from this study by having a better genetic counseling experience. We will use the answers to the questions to see if clients are accepting of the exercise and if it improves clients' genetic counseling experience. We will not give you the results of the study unless you are interested and contact us for results. We will let the research community know about the results of the study.

As another option, you do not have to participate in this study. If you decide not to participate in the study, then your genetic counseling care will not change in any way from normal client care. If you change your mind about participating in the study, then you can stop being in the study at any time.

If you complete all parts of the study, we will give you a \$15 gift card to thank you for participating.

Do you have any questions? You may contact the primary researcher on this study, Lori Erby at (301) 443-2635, about any further questions or problems with this work.

Would you like to join the study?

If yes, please arrive 15 minutes early to your appointment and the study representative will give you the first survey when you arrive.

The National Institutes of Health reviews NIH staff researchers at least yearly for conflicts of interest. I can give you a link that contains details about this process. Would you like this link? (if yes: <http://ethics.od.nih.gov/forms/Protocol-Review-Guide.pdf>). You may ask your research team for additional information or a copy of the Guide.

If you agree to the terms of the study and are willing to participate, you may proceed to verbally consent. Your consent means that you have been informed of the study's purpose, its procedures, and the possible risks and benefits. Your consent means that you have been given a chance to ask questions before you consent. Your consent means that you have voluntarily agreed to be in this study. If you are willing to participate, please verbally consent now.

Researchers Contact Information:

Anna K. Chassevent BA
Associate Investigator
Genetic Counseling Graduate Student
JHU/NHGRI Genetic Counseling Program
(360)852-0849

Lori Erby, ScM, CGC, PhD
Principal Investigator, NHGRI
Director, JHU/NHGRI
Genetic Counseling Training Program
(301) 443-2635

WRITTEN CONSENT FOR GENETIC COUNSELOR PARTICIPANTS



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service



Social and Behavioral Research Branch
National Human Genome Research Institute
National Institutes of Health
31 Center Drive (31/B1B36) – MSC 2073
Bethesda, MD 20892-2030
(301) 443-0283 - ph, (301) 480-5008 - fax

Study Title: Is it Feasible?: Self-Affirmation for Hereditary Breast and Ovarian Cancer Genetic Counseling

Principal Investigator: Barbara Biesecker

Dear Genetic Counselor,

You are invited to participate in a study conducted by researchers at the National Institutes of Health.

Why is this study being done?

This study has two main goals. First, to learn more about the acceptability of a self-affirmation intervention to clients and counselors. Second, to understand what outcomes are most important for follow-up research using self-affirmation in a genetic counseling setting.

Who can take part in this study?

You must be a genetic counselor who sees hereditary breast and ovarian cancer clients at one of our partner hospitals.

What is involved in this study?

Some of your clients will be invited to enroll in the study. They will be asked to complete a brief intervention or control prior to your visit. You will then be asked to complete a brief (2-5 min) survey after each client who is participating in the study about the client's engagement in the session. We plan to enroll 35-40 clients at your site. You will also be asked to complete a 10-15 min survey at the end of the study about your opinions on the intervention.

What are the risks of the study?

There are no known risks of taking part in this study. You may choose not to fill out any survey question. The after-visit surveys will take a few minutes after the appointment, which could increase stress on a busy day.

Are there benefits to taking part in the study?

You will not personally receive any benefits from taking part in this study. We hope to learn more about if self-affirmation improves client communication and if it is acceptable to clients and genetic counselors.

Do I have to participate?

No, you do not have to take part in this study if you do not want to.

Will I be compensated for participating?

Yes, you will receive a \$1,400 gift card.

Who else will know that I am in the study?

The counselors in this study will work closely with the research team. Clients who are involved in the study will also know that you are participating in the research protocol. Any published information will not identify the counselors involved in the research protocol.

How do I participate?

You can participate by completing this form and the subsequent questionnaires.

Thank you for your interest and time!

The National Institutes of Health reviews NIH staff researchers at least yearly for conflicts of interest. The following link contains details on this process:

<http://ethics.od.nih.gov/forms/Protocol-Review-Guide.pdf>. You may ask your research team for additional information or a copy of the Guide.

If you agree to the terms of the study and are willing to participate, you may proceed sign below. Your consent means that you have been informed of the study's purpose, its procedures, and the possible risks and benefits. Your consent means that you have been given a chance to ask questions before you consent. Your consent means that you have voluntarily agreed to be in this study. If you are willing to participate, please sign below.

I have read the explanation about this study and have been given the opportunity to discuss it and to ask questions. I hereby consent to take part in this study.

Signature of Genetic Counselor

Date

Print Name

Researchers Contact Information:

Anna K. Chassevent BS
Associate Investigator
Genetic Counseling Graduate Student
JHU/NHGRI Genetic Counseling Program
(360)852-0849

Barbara Biesecker, MS, CGC, PhD
Principal Investigator, NHGRI
Director, JHU/NHGRI
Genetic Counseling Training Program
(301) 496-3979

APPENDIX B: INTERVENTION AND CONTROL ACTIVITY

Cover page

Thank you for participating in this joint research project between the NIH and St. Luke's Health System. We appreciate your time and thoughtful participation. Please complete the following activity and survey. Give this packet to your genetic counselor during your appointment today.

For this study to remain anonymous you will be asked to develop a code word. We will need to analyze all your documents together and the code word will allow us to assemble them. The code word will be created by combining the name of the first street that you grew up on with the name of your first pet. For example: Elm-mojo. If you do not have a pet, you can choose another name that is easy to remember (not your own). It is best for the code-word to be easy to remember because you will be asked for the same code-word to label your after-appointment survey.

Code word (First street you grew up on + first pets name ex. Elm-mojo): _____

Values Writing Activity A:

Code word (First street you grew up on + first pets name ex. Elm-mojito): _____

Rank the following items in the chart from 1-11 by what is most important to you. 1 being most important.

Rank (1-11)	Item
	Artistic skills
	Athletics
	Business/money
	Creativity
	Independence
	Music
	Politics
	Relationships with friends and family
	Religious values
	Sense of humor
	Spontaneity

From the list above choose the item that is most important to you. Write about why it is important to you and how you have used it in everyday life, if possible, describing specific occasions on which this item determined what you did (*use other reverse side for more space*).

How important is this item to you?

1 2 3 4 5 6 7
Very important Unimportant

Code-Word _____

Self-evaluation questionnaire

A number of statements which people have used to describe themselves are given below. Read each statement and then circle the most appropriate number to the right of the statement to indicate how you feel right now, at this moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

	Not at all	Somewhat	Moderately	Very much
1. I feel calm	1	2	3	4
2. I am tense	1	2	3	4
3. I feel upset	1	2	3	4
4. I am relaxed	1	2	3	4
5. I feel content	1	2	3	4
6. I am worried	1	2	3	4

Code word (First street you grew up on + first pets name ex. Elm-mojo): _____

Values Writing Activity B:

Rank the following items in the chart from 1-11 by what is most important to you. 1 being most important.

Rank (1-11)	Value
	Artistic skills
	Athletics
	Business/money
	Creativity
	Independence
	Music
	Politics
	Relationships with friends and family
	Religious values
	Sense of humor
	Spontaneity

From the list above select your 9th most important item. Write a few sentences about why it is important to someone else (*use other reverse side for more space*).

How important is this item to you?

1 2 3 4 5 6 7
Very important Unimportant

Code word _____

Self-evaluation questionnaire

A number of statements which people have used to describe themselves are given below. Read each statement and then circle the most appropriate number to the right of the statement to indicate how you feel right now, at this moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

	Not at all	Somewhat	Moderately	Very much
1. I feel calm	1	2	3	4
2. I am tense	1	2	3	4
3. I feel upset	1	2	3	4
4. I am relaxed	1	2	3	4
5. I feel content	1	2	3	4
6. I am worried	1	2	3	4

APPENDIX C: CLIENT SURVEY

Email Address Request

Please provide your email address to receive the follow up survey:

Please provide the following demographic data about yourself

Racial Background (*Please check all that apply*)

☐ American Indian or Alaska Native

☐ Asian or Pacific Islander

☐ Black

☐ White

☐ Other: _____

Education

- ☐ Some high school
- ☐ High school graduate
- ☐ Some college
- ☐ College graduate
- ☐ Graduate School

If yes, when were you diagnosed? _____

Circle or check mark the selection that is most true for you

If yes, do you plan to have genetic testing?

☐ Yes ☐ Not offered

☐ Maybe ☐ I already have my genetic testing results

☐ No

How likely are you to get regular mammograms?

1 2 3 4 5 6 7

Extremely unlikely Extremely likely

Which best describes your plans to talk with your family members about genetic testing results
(check the one answer that is most true for you)?

- ☐ I don't plan to talk to anyone.
- ☐ I plan to talk to only a few people who are closest to me.
- ☐ I plan to talk to some of my family members
- ☐ I plan to talk to most of my first and second-degree relatives who are at risk for cancer
(children, brothers and sisters, parents, grandparents, aunts/uncles)
- ☐ I plan to talk to almost all my first and second-degree relatives who are at risk for cancer
(children, brothers and sisters, parents, grandparents, aunts/uncles)
- ☐ I plan to talk to almost all my family members

How likely are you to share results with the relatives you selected?

1	2	3	4	5	6	7
Extremely unlikely						Extremely likely

Section 2:

Below are listed some items involved in making an informed choice about genetic testing. Please show how confident you feel in doing each by circling the number from 1 (not at all confident) to 5 (very confident) for each item listed below.

I feel **confident** that I can:

1. Get the facts about the genetic testing choices available to me from my genetic counselor.

1	2	3	4	5
Not at all confident				Very confident

2. Get the facts about the benefits different choices related to my cancer risk

1	2	3	4	5
Not at all confident				Very confident

3. Get the facts about the risks different choices related to my cancer risk

1	2	3	4	5
Not at all confident				Very confident

4. Understand the information enough to be able to make a choice about genetic testing

1	2	3	4	5
Not at all confident				Very confident

5. Ask questions of my genetic counselor without feeling dumb

1	2	3	4	5
Not at all confident				Very confident

6. Express my concerns about different choices to my genetic counselor

1 2 3 4 5
Not at all confident Very confident

7. Ask for advice from my genetic counselor about my cancer risk

1 2 3 4 5
Not at all confident Very confident

8. Figure out the choice that best suits me

1 2 3 4 5
Not at all confident Very confident

9. Handle unwanted pressure from others in making my choice

1 2 3 4 5
Not at all confident Very confident

10. Let the genetic counselor know what's best for me

1 2 3 4 5
Not at all confident Very confident

11. Delay my decision if I feel I need more time

1 2 3 4 5
Not at all confident Very confident

12. Take actions that will help prevent or minimize my risk of cancer

1 2 3 4 5
Not at all confident Very confident

Section 3:

Complete the following questions with what is most true for you.

1. I am clear in my own mind why I am attending the clinical genetics service

1 2 3 4 5 6 7
strongly disagree strongly agree

2. I can explain what my hereditary cancer risk means to people in my family who may need to know

1 2 3 4 5 6 7
strongly disagree strongly agree

3. I understand the impact of my hereditary cancer risk on my child(ren)/any child I may have

1 2 3 4 5 6 7
strongly disagree strongly agree

4. When I think about the condition in my family, I get upset
1 2 3 4 5 6 7
strongly disagree strongly agree
5. I don't know where to go to get the medical help I/my family need (s)
1 2 3 4 5 6 7
strongly disagree strongly agree
6. I can see that good things have come from having this condition in my family
1 2 3 4 5 6 7
strongly disagree strongly agree
7. I can control how this condition affects my family
1 2 3 4 5 6 7
strongly disagree strongly agree
8. I feel positive about the future
1 2 3 4 5 6 7
strongly disagree strongly agree
9. I am able to cope with having this cancer risk in my family
1 2 3 4 5 6 7
strongly disagree strongly agree
10. I don't know what could be gained from each of the options available to me
1 2 3 4 5 6 7
strongly disagree strongly agree
11. The possibility of having an elevated cancer risk in my family makes me feel anxious
1 2 3 4 5 6 7
strongly disagree strongly agree
12. I don't know if my cancer risk could affect my other relatives (brothers, sisters, aunts, uncles, cousins)
1 2 3 4 5 6 7
strongly disagree strongly agree
13. In relation to the cancer risk in my family, nothing I decide will change the future for my children/any children I might have
1 2 3 4 5 6 7
strongly disagree strongly agree
14. I understand the reasons why my doctor referred me to the clinical genetics service
1 2 3 4 5 6 7
strongly disagree strongly agree

[illegible]

1 2 3 4 5 6 7
strongly disagree strongly agree

1 2 3 4 5 6 7
strongly disagree strongly agree

1 2 3 4 5 6 7
strongly disagree strongly agree

[illegible]

1 2 3 4 5 6 7
strongly disagree strongly agree

1 2 3 4 5 6 7
strongly disagree strongly agree

1 2 3 4 5 6 7
strongly disagree strongly agree

[illegible]

1 2 3 4 5 6 7
strongly disagree strongly agree

Circle the option that is most accurate regarding Hereditary Cancers:

1. All people who have an altered cancer gene will get cancer
True False
2. If an altered cancer gene is found, the related cancer can always be prevented or cured
True False
3. The sibling or child of someone with an altered cancer gene has a 50% risk of having the same altered gene
True False
4. A person who's genetic testing does not find an altered cancer gene can still get cancer
True False
5. People who have genetic testing will always get clear positive or negative results
True False
6. All people who have multiple family members with cancer qualify for genetic testing
True False
7. If someone has an altered cancer gene screening and healthy behaviors can reduce their risk of dying from cancer
True False

Section 5:

Regarding the writing activity that you completed prior to your genetic counseling visit, circle the selection that most aligns with your experience:

1. Were you able to finish the values writing activity?
Yes No

If not, what was the reason that you did not complete the activity?

2. The values writing activity affected my appointment?
Yes No

If yes, how did the activity affect the appointment?

3. The values writing activity improved my interaction with my genetic counselor
Yes No
4. The values writing activity hindered with my interaction with my genetic counselor
Yes No
5. Please list any other thoughts you have about completing the writing activity.

Address Request

If you would like to receive a \$15 gift card for your participation, please include your name and address here. This information will be kept separate from your study documents.

APPENDIX D: GENETIC COUNSELOR AFTER VISIT SURVEY

DATE:

CLIENT CODE WORD:

Complete the following questions regarding the client in your last counseling session.

1. This client is clear in her own mind why she is attending the clinical genetics service

1 2 3 4 5 6 7
strongly disagree strongly agree

2. This client could explain what her cancer risk means to people in her family who may need to know

1 2 3 4 5 6 7
strongly disagree strongly agree

3. This client understands the impact of her cancer risk on her child(ren)/any child she may have

1 2 3 4 5 6 7
strongly disagree strongly agree

4. When this client thinks about the cancer risk in her family, she gets upset.

1 2 3 4 5 6 7
strongly disagree strongly agree

5. This client doesn't know where to go to get the medical help she/her family need(s)

1 2 3 4 5 6 7
strongly disagree strongly agree

6. This client can see that good things have come from having this condition in her family

1 2 3 4 5 6 7
strongly disagree strongly agree

7. This client feels that she can control how her cancer risk affects her family

1 2 3 4 5 6 7
strongly disagree strongly agree

8. This client feels positive about the future

1 2 3 4 5 6 7
strongly disagree strongly agree

9. This client is able to cope with having this condition in her family

1 2 3 4 5 6 7
strongly disagree strongly agree

10. This client doesn't know what could be gained from each of the options available to her

1	2	3	4	5	6	7
strongly disagree						strongly agree

11. The possibility of having an elevated cancer risk in her family makes this client feel anxious

1	2	3	4	5	6	7
strongly disagree						strongly agree

12. This client doesn't know if her cancer risk could affect her other relatives (brothers, sisters, aunts, uncles, cousins)

1	2	3	4	5	6	7
strongly disagree						strongly agree

13. In relation to the cancer risk in her family, this client feels that nothing she decides will change the future for her children/any children she might have

1	2	3	4	5	6	7
strongly disagree						strongly agree

14. This client understands the reasons why her doctor referred her to the clinical genetics service

1	2	3	4	5	6	7
strongly disagree						strongly agree

15. This client knows how to get the non-medical help she/her family need(s) (e.g. educational, financial, social support)

1	2	3	4	5	6	7
strongly disagree						strongly agree

16. This client can explain what her cancer risk means to people in her family who may need to know

1	2	3	4	5	6	7
strongly disagree						strongly agree

17. This client doesn't feel that she knows what she can do to change how her cancer risk affects her or her children

1	2	3	4	5	6	7
strongly disagree						strongly agree

18. This client doesn't know who else in her family might be at risk for familial cancer

1	2	3	4	5	6	7
strongly disagree						strongly agree

[illegible]

1 2 3 4 5 6 7
strongly disagree strongly agree

1 2 3 4 5 6 7
strongly disagree strongly agree

1 2 3 4 5 6 7
strongly disagree strongly agree

1 2 3 4 5 6 7
strongly disagree strongly agree

1 2 3 4 5 6 7
strongly disagree strongly agree

APPENDIX E: PATIENT STUDY INFORMATION



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service



Social and Behavioral Research Branch
National Human Genome Research Institute
National Institutes of Health
31 Center Drive (31/B1B36) – MSC 2073
Bethesda, MD 20892-2030
(301) 443-0283 - ph, (301) 480-5008 - fax

Are you interested in participating in research to improve our genetic counseling appointments?

Study Name: Is it Feasible?: Self-Affirmation for Hereditary Breast and Ovarian Cancer Genetic Counseling

Principal Investigator: Lori Erby

Anna Chassevent, a student working on this study, will call you in the next few days talk more about the study and confirm if you would like to participate. If you would not like to be contacted, please let the St. Luke's clinic coordinator know or call Lori Erby at (301) 443-2635.

Why is this study being done?

For this project, we are studying a way to improve your genetic counseling experience. We are looking to see if a short writing exercise before your appointment can help improve the outcomes of genetic counseling appointments.

Why was I asked to join this study?

All female clients being seen in the St. Luke's Health System Hereditary Breast and Ovarian Cancer clinic for genetic counseling are given the opportunity to participate in this study. This study is a collaboration between the genetic counselors at St. Luke's Health System and researchers at the National Institutes of Health (NIH).

What will I be asked to do?

You will be asked to arrive **15** minutes early to your appointment to fill out a survey and a short writing exercise about things that are important to you. After your appointment, we will ask you to complete a follow-up survey either in the medical office or online. The survey should take **10-15 min**. If to be completed online, we will give you the link to access the survey.

What are the risks of the study?

There are no health risks to participating in this study. There is a risk that someone outside the study will see your study information. We will do our best to keep your information safe by storing it on a secure computer. We will not record your name. Instead, we will ask you to create a code word. If we share your information with other

researchers, we will ask them to use the same protections. If you are pregnant, there are no additional risks to your fetus from participation in this study.

What are the benefits for this study?

You may benefit from this study by having a better genetic counseling experience. We will not give you the results of the study unless you are interested and contact us for results. We will let the research community know about the results of the study.

Do I have to participate?

You do not have to participate in this study. If you decide not to participate in the study, then your genetic counseling care will not change in any way from normal client care.

Will I get anything for participating?

If you complete all parts of the study, we will give you a \$15 gift card to thank you for participating.

What if I have more questions?

We will call you in a few days to discuss this study. You may also contact the primary researcher on this study, Lori Erby at (301) 443-2635, about any further questions or problems with this work.

The National Institutes of Health reviews NIH staff researchers at least yearly for conflicts of interest. For more information, you can go to:

<http://ethics.od.nih.gov/forms/Protocol-Review-Guide.pdf>. You may ask your research team for additional information or a copy of the guide.

A member of the research team will call you in the next few days to answer any questions and receive your consent if you are interested in participating. Your consent means that you have been informed of the study's purpose, its procedures, and the possible risks and benefits. Your consent means that you have been given a chance to ask questions before you consent. Your consent means that you have voluntarily agreed to be in this study. We look forward to talking with you.

Researchers Contact Information:

Anna K. Chassevent, BA
Associate Investigator
Genetic Counseling Graduate Student
JHU/NHGRI Genetic Counseling Program
(360) 852-0849

Lori Erby, ScM, CGC, PhD
Principal Investigator, NHGRI
Director, JHU / NHGRI
Genetic Counseling Training Program
(301) 443-2635

APPENDIX F: SELF-AFFIRMATION ESSAY TRANSCRIPTS

Essay 1:

My family and friends are the very most important thing in my life. I value relationships more than anything. Connecting with people on a personal level is what makes me smile, laugh and allows me to get through difficult times. For example, going through my divorce last year was miserable but friends and family helped me get through it.

Essay 2:

Creativity is important to others because it is how they can express emotions that are otherwise hard to express. Creativity can be expressed in a variety of ways through dance, painting, music etc. Creativity is a lot about creation of something deeply personal.

Essay 3:

Support from family and friends makes all of life better. My husband's support has helped keep me positive through years of ups and downs. Friends are there for support and humor. I think relationships with friends and family are the basis of all of the other items in the list.

Essay 4:

Friends and family are my foundation in my life. They support me with all ups and downs in life. I learn from them as well as they learn from me.

Essay 5:

My religious values for me tie in directly to my relationship with friends and family. My best friends are those people at church and religious groups who have weather my storms with me, who accept me for who I am, and who have been there for me no matter what. On a more personal note, I have grown in my faith over the past 10 years and have become quite comfortable with turning things over to God and trying to see His way for me no matter what the situation. Before my cancer diagnosis, I prayed for three things—two of which were granted (my sister to have a life-saving operation and my dog to get over a debilitating disease). My third prayer/request was to not have cancer—two out of three wasn't bad for me. I know that God is looking after me and will use me for a good purpose.

Essay 6:

I like to help to (acluny?) my granddaughter to draw and appreciate art.

Essay 7:

My relationship with God is most important to me. I know that He has a plan and a purpose for my life! It is in that relationship and through His word that I find strength, value, purpose and comfort.

Essay 8:

My husband & son love to be physical and are athletic. They say it makes them feel better.

Essay 9:

Sense of humor (No other writing).

Essay 10:

Relationships w/ friends & family are THE most important. I have learned they are here for more than ever imagined. They are all part of my village and have played vital roles in who I am & in raising my children.

Essay 11:

Used in every aspect of my life getting closer to my faith, studying the word and striving to live as such is an everyday goal.

Essay 12:

Music is relaxing, enjoyable, and is important to your sanity. I enjoy all types of music, depending on my mood as to which type I listen to.

Essay 13:

Religious values (No other writing)

Essay 14:

Athletics, not my thing I don't care for sport. But I don't mind working out for myself.

Essay 15:

People use their creativity. Artistically – maybe reduce stress

Essay 16:

My prayers are important because I know God is already working on my day to help me through. My artistic skills is something that has been a part of my life since my grandmother taught me to sew at the age of 5.

Essay 17:

Relationships with my family and friends is most important because they are the people that make my life awesome.

Essay 18:

Relationships with friends and family (No other writing)

Essay 19:

Creativity is most important because it applies to every area of life, not just artistically but intellectually. If you are creative you can problem solve by thinking outside the box. I left care @ KUMC to see Dr. P---- because I was thinking creatively.

Essay 20:

My Catholic Faith has made me the independent, hopeful, joy filled person that I am today. It is because of my Faith that I was able to leave my family and abuse and venture of on my own. I knew I wouldn't be alone and that God would place new safe people in my life who would be there as my new family. My Faith has allowed me to travel to various countries on mission trips and develop a desire to serve those in need. It is because of God that I have the trusting, honest relationships I have today. He brought the perfect role-models into my life and the reason I am forever grateful for His love.

Essay 21:

Artistic skills will be important to someone if it drives their daily life. If your job or mental well-being is positively impacted by improving or using these skills, their importance would be more significant.

Essay 22:

My relationship with my friends and family have always been so important to me ~ especially my family. At this stage of my life I feel truly blessed to still have both of my parents, a wonderful husband and one terrific, smart and kind college student. I often will go to different family members for advice and guidance on various things in my life. For example, I am very much a career woman and as different work opportunities have presented themselves, I will go to my dad who was very successful in business. He

always has a different perspective and helps me sort through things. I recently turned down a career move after a detailed conversation with my dad ~ and I'm glad I did because a better opportunity presented itself. I will discuss with my husband stress or anxiety about really anything ~ He knows me inside and out and is my best friend in the world. I laugh the most with my husband.

Essay 23:

Music is important to others because they may use it to express themselves.

Essay 24:

Religious values-having a moral compass/ guide and solid foundation of faith helps with any and everything in life

Essay 25:

Family is everything to me. I have lost most of my family so throughout my life I have considered many of my friends family. Family are the ones that are there for you no matter what. They know everything about you, the good, the bad the ugly, and they still love and support you.

All I ever wanted to be was a mother and now that I have children they are my world. I would do anything for them. And luckily, they have grown up to love each other and are there for each other. Family is my number 1!

Essay 26:

Artistic skills may be important to someone if that is their livelihood.

Essay 27:

They are into design, appearance is important to them.

Essay 28:

My relationships with family and friends are the most important to me because things can go wrong unexpectedly but you can always count on them to have your back. No matter how stressful my day gets I know I can go home and they will be there to brighten my day. I know they are who will be there in my highest points and at my lowest points. They don't care about my money or skill sets or any of that, they love me for who I am as much as I love them and in the end, that's really all you need in life to be happy.

Essay 29:

My family is always 1st for me. I could have already planned something to do for a day, but if my kids call I'll change it so I can go with them.

I can sit in a room with family – sit back and watch them talking and laughing and all I can do is smile. Our Love and Friendship as a family is wonderful.

Essay 30:

Without friends and family, I would be lost and bored.

Essay 31:

Creativity is a skill that people bring to the table. Creativity is valued because it varies so much among people and can produce an immense amount of growth within organizations of any kind. Creativity brings solutions.

Essay 32:

From an early age, my religious values were something instilled in me by my parents, and then later on I adapted and adjusted my beliefs based on my outlook on life. I owe everything I have and I am due to my faith and religious beliefs. God has been a constant support system and someone to lean on. Every milestone in my life, I have used my faith to have faith in the journey (college, nursing school, CRNA school, and starting a family of my own) and not lean on my own understandings.

Essay 33:

My relationship w/Jesus Christ is the most important in my life, because w/o Him I would not have life. When I feel stressed or frustrated or upset, all I have to do is pray for help and guidance and I feel at peace.

Essay 34:

Money tends to be a symbol of success and happiness. Generally, speaking, business is what generates money. Someone else can easily identify with the amount of money earned/acquired. The more money, the better perceived someone may think they are. Conversely, the lack of money may cause someone else to feel inferior.

Essay 35:

God is my #1 priority I put him first in my everyday life. Church on TV every day. Pray Daily, I Know everything is possible with God!

Essay 36:

Some people are artistic some are not. If they are good at it I'm sure it's important to them.

Essay 37:

Independence is most important to me because I have MS. I have been blessed to always be able to maintain my independence for the past 29 years following my diagnosis. This allows me to do all the things I want to do, mainly volunteering and was able to continue to work until this past year doing what I love. ... nursing!

Essay 38:

Business & money are the staples of life. Unless you're born w/a silver spoon in your mouth you will need to work, make money & be involved in business. At this stage in my life in the "world of work" for me, has turned into opportunities of service. This could be true of more retired persons.

Essay 39:

Athletics and sports in general I believe is a way to bring people together and form common bonds, rivalries, inspire bonding, and pride. Performing in athletic activities also can be a moral boost, stress reliever and other arenas for a sense of accomplishment.

Essay 40:

Spontaneity is the spice of life. The world is ever changing and you must be willing to change with it or you will be left behind.

Essay 41:

Music: I don't know. Perhaps it makes them feel good to listen to music, gives them enjoyment. Perhaps it helps them to relax.

Essay 42:

I teach business education. I want to teach teenagers how to be prepared for real world careers and financing. As an educator, budgeting effects my life personally. Knowing how to successfully manage your business and finances will reduce stress in your life!

Essay 43:

Money & Business are some peoples priority because they are driven to be successful in other peoples eyes. Money is a necessary item to live, but shouldn't be a top priority.

Essay 44 (Removed from analysis):

1. Friends & family is what I live for.
2. My religion has helped me through hard times
3. I have always felt independence to stand as women power very important to me.
4. My job is very important to take care of bills
5. Making someone smile or happy makes me smile
6. Do art work feels good just don't have enough time
7. I work out every morning M-F to do my best is important
8. Country music
9. Goes with my 6

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APPENDIX H: CURRICULUM VITA

Anna K. Chassevent

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Education

- 2015-current Genetic Counseling - Master of Science
Johns Hopkins University, Baltimore, Maryland
GPA: 3.73/4.0
- 2012-2015 46 credits toward PhD in Healthcare Genetics
Clemson University, Clemson, South Carolina
GPA: 3.82/4.0
Relevant course work: Bioinformatics, Molecular Genetics,
Advanced Genetics, Pharmacogenomics
- 2008- 2012 Psychology (Honors) - Bachelor of Arts
Anderson University, Anderson, South Carolina
GPA: 3.93/4.0

Clinical Rotation Experience

- Oct.-Dec., 2017: Undiagnosed Diseases Network, National Institutes of Health
- Sept.-Oct., 2017: Clinical Cancer Genetics Program, Johns Hopkins Hospital
- June-July, 2017: National Human Genome Research Institute, National Institutes of Health
- March-May, 2017: Center for Advanced Fetal Care, Mercy Medical Center
- Oct.-Dec., 2016: National Institute of Neurological Disorders and Stroke, National Institutes of Health
- Sept.-Oct., 2016: General Genetic Clinic, Johns Hopkins Hospital
- June-Aug., 2016: Pediatric Neurogenetics, Kennedy Krieger Institute
- March-May, 2016: Perinatal Center, MedStar Washington Hospital System
- Jan.-March, 2016: Commercial Laboratory, GeneDx

Oct.-Dec., 2015: Maternal/Fetal Medicine, Howard County General Hospital

Professional Work Experience

Aug., 2015-
Current: Pre-Doctoral Fellow, National Human Genome Research Institute (NHGRI), National Institutes of Health. Research surrounding genetic counseling concerns to advance the professional field.

Jan. - May, 2015: Graduate Research Assistant, School of Nursing Clemson University, Clemson, SC. Coordinated with the Sullivan Center and the Healthcare Genetics program to establish a breast cancer screening program for high risk patients in the community.

Aug., 2013-
May, 2015: Graduate Teaching Assistant, School of Nursing Clemson University, Clemson, SC. Responsible for lesson plans, lectures, grading, facilitation of class discussions, and leading undergraduate students in research for Genetics and Creative Inquiry courses.

Jan. - May, 2012: Supplemental Instruction Facilitator, Anderson University, Anderson, SC. Worked with the Student Success Center to establish the Supplemental Instruction program. Planned and taught supplemental class lessons twice a week and facilitated communication between the professor and students to maximize student learning for a Psychology 101 course.

Research Experience

Master's Thesis: "Is it Feasible?: Self-Affirmation for Hereditary Breast and Ovarian Cancer Genetic Counseling." A randomized controlled feasibility study of an established psychosocial intervention applied in a novel hereditary cancer genetic counseling clinic.

Aug., 2013 –
May, 2014: Observed and interviewed clinicians in a behavioral pediatric department about their knowledge and use of genetics in the clinic, created a presentation targeted to their requests, analyzed knowledge differences using a pre-and post-test before and after the presentation. Presented this research at The American Society of Human Genetics annual meeting.

Jan. - May, 2013: Lab assistant for Fulbright Research Scholar, Dr. Geraldine Sanchez, at Clemson University. The research project assessed the effect of four types of mushroom extracts on mediating symptoms in female diabetic mice. Administered extract treatments and collected data on feed and water intake, vaginal cytology, temperature, and environmental factors.

- June – Aug., 2011: Lab assistant for Dr. Andy Norris at the Cancer Research Center at Anderson University. Applied photodynamic therapy to *Saccharomyces cerevisiae* to assess the therapy's effectiveness in targeted cell death. Evaluated the use of various essential oils as anesthetics in *Danio rerio*.
- June – Aug., 2010: Research assistant for Dr. Stephen Meharg at the Center for Memory and Learning in Longview, WA. Administered adult and children's intelligence and memory assessments in addition to administering malingering tests and inputting data for Dr. Meharg's clinical research.

Presentations

Chassevent, A. (2017). Presymptomatic Genetic Testing for Adult Onset Cancer Syndromes in Minors. *Post clinic conference*, NIH, Bethesda, Maryland.

Chassevent, A. (2016). Is it Feasible?: Self-affirmation for hereditary breast and ovarian cancer genetic counseling. *Thesis oral exams*, Johns Hopkins University, Baltimore, Maryland.

Chassevent, A. (2016). Shared decision making: When values differ. *Post clinic conference*, NIH, Bethesda, Maryland.

Chassevent, A. & Myers, R. (2014). Metabolic pathways & drug metabolism. *Pharmacogenomics: a key to personalized medicine*, Greenville, South Carolina.

Chassevent, A. & Darabi, S. (2014). Effectiveness of personalized genetic education modules. *American Society of Human Genetics 2014 Annual Meeting*, San Diego, California.

Jenks (maiden name), **A.** (2014). Genetics in the clinic: Autism spectrum disorder. *Greenville Health System Developmental-Behavioral Pediatrics Department*, Greenville, South Carolina.

Jenks, A. (2013). Hepatitis C virus. *Advances in Healthcare Genetics with Application to Patient Care*, Greenville, South Carolina.

Darabi, S. & **Jenks, A.** (2013). The effect of strawberry extract on the proliferation of pancreatic cancer cells. *HEHD Research Forum*, Clemson, South Carolina.

Jenks, A. (2012). The present and future of behavioral genetics as related to the stress response. *National Conference on Undergraduate Research*, Ogden, Utah

Selected Leadership Positions, Awards, and Volunteer Engagement

Intercity Arts Camp Volunteer, The ROC Arts Camp, 2017

Childcare and Mentoring Ministry Volunteer, The Garden Church Baltimore, 2015-current

President of the Healthcare Genetics Society, Clemson University, 2015

Secretary of the Healthcare Genetics Society, Clemson University, 2014

Vice President of Reformed University Fellowship, Anderson University, 2012

Most Outstanding Psychology Student, Anderson University, 2012

Coaches Award, Women's Golf, Anderson University, 2009

Technical skills

Genetics software and databases: ClinVar, UCSC Genome Browser, dbSNP, Human Gene Mutation Database, ExAC, PolyPhen, 1000 Genomes, ect.

Technology: EPIC, Mac OS, Windows, Microsoft Excel, Microsoft Word, Microsoft PowerPoint

Statistics: SPSSs, Stata

Intelligence, memory, and malingering assessment administration: KBIT-2, WRAT-4, RBANS, TMT, WAIS-IV, WMS-III, TOMM

Lab: Cell culture, gel electrophoresis, lab animal care and certification